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ABSTRACT

Selected papers from the 1980 World Congress of Rehabilitation International Meeting on the participation of disabled people are presented. The papers address the rights of the disabled, the organization and functions of consumer groups, the impact of consumer involvement on rehabilitation and related services, social implications of the consumer participation movement, and the coming together of the disabled throughout the world. Titles and authors include the following: "Self-Determination of Handicapped People" (M. Fritsch); "The Right to All Types of Information" (K. Karlsson); "The Right to Work: A Political Issue" (B. Lindqvist); "Consumer Groups: Their Organization and Function" (A. Simpson); "Organizing an Action Group" (J. Simkins); "Trade Union Participation" (L. Maguire); "Handicap Councils: A Swedish Experiment" (L. Gardestrom); "Participation of Handicapped People in the Planning, Implementation and Management of Rehabilitation Services" (P. Blommestijn); "Policy Issues in Independent Living Rehabilitation" (D. Galvin); "Higher Education Opportunities" (K. Konkkola); "The Disabled Consumer Movement: Policy Implications for Rehabilitation Service Provision" (J. Derksen); "Towards Full Political Participation" (B. Carlsson); and "Disability Rights Issues: The Role of Advocacy in Government (E. Fiorito). (SW)

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Participation of People with Disabilities: An International Perspective

selected papers from
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World Congress of Rehabilitation International
Winnipeg, Canada
June 22-27, 1980

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Foreword

by

Norman Acton, Secretary General
Rehabilitation International

"Participation" has become one of the most dynamic concepts being employed in efforts to understand and find solutions to the problems of disability. Thinking about it has emerged as a logical development from the examinations of normalization, integration, mainstreaming, equal rights and independent living that have dominated the discourse of the past decade.

The global nature of interest in it was demonstrated when the United Nations General Assembly adopted "Full Participation and Equality" as the theme for the International Year of Disabled Persons in 1981. Its spirit was reflected in the proposal of the Assembly's advisory committee, representing 23 nations in every stage of development, that the name of IYDP be the International Year of Disabled Persons, not the Year for them.

At the 14th World Congress of Rehabilitation International, in Winnipeg, Canada in June 1980, one of the major events was an all-day workshop on "Participation of People with Disabilities in Rehabilitation." Representatives of disabled peoples' organizations, of governments, of other organizations and of the professional and academic communities spoke about and discussed the issues involved in generating the full participation of people with disabilities in decisions affecting their lives--decisions about their individual programs for rehabilitation, about the design of the programs themselves, and about the legislation and administration through which society responds to the problems of disability.

This volume of papers, selected from those presented to the Participation Workshop and other sessions of the 1980 World Congress, presents the thinking of leaders from ten countries. It provides a global overview of the stage for development of the participation concept and its application.

An analysis of the papers shows that some of the central questions related to this topic require further exploration. What, for example, are the sociological underpinnings of "full participation?" Are there some elements, or combinations of elements that must be present before a minority group can respond effectively to a social reality that excludes its members from the participation of which they are capable? To what extent is the development of significant activity by a disadvantaged sector of a population dependent on the education, training, eco-

nomic security and political awareness of individual members? What are the roles of militancy, charisma and discipline?

These and other questions have led the publishers to see value in future publications on this subject, focusing more on the "why" and "how" of participation of people with disabilities in all areas of social life, from their own rehabilitation to the formulation of national policies. Reactions and suggestions will be welcome.

Introduction

by

Donald E. Galvin, Ph.D., Director
University Center for International Rehabilitation

A significant social movement becomes possible when there is a revision in the manner in which a substantial group of people looking at some misfortune, see it no longer as a misfortune warranting charitable consideration but as an injustice which is intolerable in society.

Turner, 1969

The University Center for International Rehabilitation (UCIR) was founded on the premise that a greater quantity and quality of information exchanged across national boundaries can significantly improve services to disabled individuals. Accordingly, the project seeks to transfer information from other countries that will improve the development and rehabilitation of individuals of all ages in the United States and to provide technical assistance to rehabilitation personnel in implementing what is transferred.

As one of our initial efforts, a conference was held at Michigan State University in March 1979 to identify those major domestic concerns or needs that might be relieved through international study. Not surprisingly, consumer participation in rehabilitation policies and service programs was identified as a topic that should be pursued by UCIR. Participants were aware that in 1975 the United Nations General Assembly had adopted a Declaration of the Rights of Disabled Persons and that in 1976 the General Assembly voted to proclaim 1981 the International Year for Disabled Persons (later to be appropriately changed to the International Year of Disabled Persons) which has as its theme "Full Participation and Equality." It was also of note that the 14th World Congress of Rehabilitation International adopted "Participation of People with Disabilities in Rehabilitation" as one of their five major congress concerns.

As Ed Roberts stated at the UCIR conference, "The future is in the young, and I don't want to see another generation of young people with disabilities become older dependent people with disabilities. I think that with the new laws, such as P.L. 94-142, and the movement for independent living across this country, we are going to see a generation that's younger, independent, dynamic, involved people who have a choice to be a part of their community and to be a part of their society. And to me, that's my dream. People with disabilities are finally joining in

that struggle and together we are going to change society fundamentally, and we are going to change the world in a way its never seen before."

In a similar view, the executive secretary of the International Year of Disabled Persons recently wrote, "In fact, disabled persons will be effectively integrated only if we can free ourselves from our panic, our taboos and the childish attitudes that hold us captive and keep alive our prejudices regarding particular categories of society who are set apart from the human race. The social rehabilitation of disabled persons would become a reality if and in so far as we succeed in radically changing our attitudes and behaviour towards disabled persons. Then and only then will we have ceased to create handicaps for these men and women, whether their disabilities are physical or mental."

The World Congress provided a vital step in the direction of changing ourselves and society. At the congress, a number of reports were given by representatives of organizations of disabled people and concerned others from a variety of countries. UCIR was particularly interested in this conference theme. Staff served as rapporteurs, participants, and systematically interviewed several of the representatives present who were disabled.

Representatives of UCIR and Rehabilitation International (RI) agreed that these reports should be made available to the world rehabilitation community, because they constitute the most comprehensive statement to date of this worldwide social movement. This collection of papers will provide the reader with an overview of participation philosophies, models, issues, and outcomes in ten countries. UCIR and RI will continue to collaborate in this effort by way of further publications and efforts to facilitate the movement for participation of people with disabilities.

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I.

Consumers: Individuals with Common Experiences

This publication begins by looking at the basic element of participation of disabled people--the disabled person. The papers included in this chapter illustrate some of the many experiences that disabled people share. Dr. Marianne Fritsch from the Federal Republic of Germany discusses self-determination of handicapped people in several aspects of life; Bernard Lesigne from France looks at the everyday lives of disabled people in his country; Karl-Erik Karlsson from Sweden discusses disabled persons' rights to information, and Bengt Lindqvist from Sweden analyzes the right to work from a political perspective. Chapter 2 will look at disabled people coming together and acting together in groups.

SELF-DETERMINATION OF HANDICAPPED PEOPLE

Dr. med. Marianne Fritsch, Director
Senator Neumann Home for the Chronically Ill, Fed. Rep. of Germany

Is it only an inflammatory word in modern handicap work? Does it depict a dislocation of responsibility from the legislature to social work? Or does self-determination of the disabled represent a belated declaration of age for citizens of age?

The constitution of the Federal Republic of Germany sets forth, in Article 1, the supreme law of the country: The dignity of man is inviolable. Human dignity is a deeply felt part of man's intrinsic value and independence; dignity confers an inner and a social recognition of the value of each person for his own sake.

Each human being, including the disabled, is a person gifted with the ability of leading his life under his own supervision and responsibility. Extensive development of his personhood must be guaranteed.

The second article of the German constitution states: Everyone has the right of free development of his personality as long as he does not violate the rights of others and does not transgress constitutional order and moral law. The right of self-determination is thus guaranteed to every German, including the handicapped. However, this law imposes restrictions on the individual members of a community such that, for example, the intimate sphere of a fellowman or the interests of the community may not be considerably disturbed.

Also in Article 2, the right to live is expressly confirmed. Human life represents a maximum value within the constitutional order. It is the vital basis of human dignity and the assumption of all other basic laws. This right to live also includes an entitlement to social welfare for cases of indigence in order to protect life.

Article 3 of the basic laws says: All human beings are equal before the law. Consequently, the handicapped are not a minority having to struggle for social acceptance. If you compare Article 3 with the principles stated in the United Nations' Declaration on Rights of Handicapped Individuals, the same statements can be found therein.

But what does reality look like?

In our institution of severely handicapped youth I have asked individuals and groups of different ages with diverse disabilities to express their opinion regarding self-determination of the disabled. All stated that they do not feel restricted in their interests, such as voting, participation in social and political life, freedom to choose their religion, nor in their self-determination. However, they see difficul-

ties due to their dependence on care, social welfare and institutionalization.

Coping with Disability

The main problem mentioned by all was coping with their individual disability in the first place. Everyone still entertains hope that there will sometime be the possibility of healing his disability, though all of them are aware that it will not be the case with their individual handicap. Individuals handicapped since birth, for example those with cerebral palsy, can arrange themselves far better in the course of time than MS patients or those injured in accidents.

Some students mentioned that they had not perceived their handicap as intensely when they were children, because they had been securely sheltered in their parents' home and believed in miracles. Only with puberty and intellectual development did they begin to realize what kind of life they would have to lead.

Not being able to dance was a major concern. Dancing gives expression to the joy of life and the possibility of moving freely. They are excluded from it because they are sitting in their wheelchairs. This is when the thought arises: Why do I have to be disabled? With this, the stigma is born and accompanies them throughout life. Feelings of guilt play a considerable part. Fury, despair, lethargy, and loss of control are expressions of this quarrel with the disability as a part of one's own self.

An older handicapped woman told me: "In the past the disability possessed me; I felt as if I was tied down. But now I possess the disability and I feel free making decisions. This is the difference!"

Barriers to Independence in Decision Making

How free are handicapped people in making their decisions? How inviolable is their human dignity? Can they really develop their personality as freely as every nonhandicapped person?

A handicapped person whose disability is not so severe as to require special care or to require substantial social welfare assistance has greater latitude in his choices compared to a severely handicapped person. He has free choice of residence (Article 11, Basic Laws). However, if he requires a flat meeting the conditions of the disabled, a corresponding flat will be assigned to him by the Administration for Accommodation, not always located in the area he preferred.

If he requires constant assistance for all daily activities, then there is the possibility of admitting him as a helpless person into an institution such as ours. Though he will have to give his permission to being admitted, there is seldom any other alternative. In such an institution his personal freedom will be somewhat restricted in favor of the rights of the community. In the beginning he may have no influence on his preferred accommodation. For example, he may be assigned to a multiple bedroom. He can neither choose the attendants and other care givers, nor his doctor or therapist when he is in the hospital. The time schedule for meals, getting up and going to bed are all fixed.

He signs a contract of care with the institution, which can be annulled reciprocally. With this document he gets needed help and, unfortunately, even overprotection. The handicapped person himself may determine the extent of the care he needs. If institutional placement is likely to be permanent, the handicapped person is tempted to overestimate the amount of care needed; if he does not see any sense in helping himself, the personal attention will be more valuable to him.

Relationships with Others

When I asked a handicapped woman whether the relationship between a handicapped patient and the care staff resembles matrimony, she replied that it is a sort of partnership with constantly changing partners which, however, is inextricable for the handicapped person. The disabled person must constantly explain, postulate and show what kind of help he requires. That turns daily care into a problem. The whole day consists of a sequence of compromises. For both parties concerned, sympathy and antipathy result from the interaction; however, the handicapped person is in the situation of dependency.

This is also applicable to the handicapped at home, who are dependent either on their partners or on visiting nurses. Imagine a paralyzed person having to use the bathroom urgently when the nurse has no time to assist him. Then only the decision of letting go and getting wet will help. Only a handicapped person having experienced such a situation will know what it means to ask the nurse to clean it up again.

Another handicapped woman (with tetraplegia) told me regarding the subject of lodging: "I had to abandon my flat, because I was single and could not get any help. Consequently, I became separated from my friends, could no longer make my own decisions and had to give up my independence. I was 45 years old when the accident happened, and I am physically totally dependent on others."

But she experienced some positive aspects in her predicament. She loves life and has no financial problems, very good medical care,

no further housing problems, new friends and the possibility of interceding for others, as well as realizing that the nondisabled have to face problems in life. She learned tolerance and the will to have a positive outlook on life.

The handicapped in our institution choose their own intimate acquaintances. Very often people of the surrounding area who are socially and humanistically inclined come to our house, have discussions, organize little excursions with our handicapped, and sometimes offer better advice to them in questions of life because they have kept a certain distance.

Our younger disabled welcome accommodations in a home for the disabled. In such a home they do not feel alone and are not constantly faced with the nondisabled. Often all of them drive home for the weekend. However, they would prefer smaller bedroom units, such as single- or double-rooms. Once in a while, they would like to have the possibility of retiring undisturbed. An intimate sphere cannot be granted to an individual in a multiple bedroom. In this respect, the demands of the United Nations' declaration #9 cannot be considered satisfactorily met because of financial reasons.

It still remains a dream of the future to guarantee all handicapped a nurse at home, if possible, or to create institutions in which the disabled live in apartments with corresponding services.

In our institution, it is possible to reintegrate annually 10% of our patients in an apartment of their own or in their families, whereas the others will stay for a lifetime.

Barriers to the Enjoyment of Leisure Time

According to the law governing the accommodation of disabled in special homes and institutions, our institution has an advisory council which is elected from our handicapped. The council has the right of cooperation in organization of the course of events such as preparing the bill of fare, furnishing rooms, organizing parties, and suggesting ideas of how to spend leisure time.

A fundamental point of self-determination is the organization of leisure time. The institution offers many possibilities for individual formation of groups and manages essential arrangements with local boards. However, it leaves it up to the individual himself to articulate his wishes and to realize them.

Unfortunately the realization of individual holiday leisure time for the more severely handicapped and wheelchair users comes up against

the difficulty that corresponding opportunities are relatively few due to architectural problems. So the disabled finds himself together again with other handicapped individuals. Consequently, he cannot be on holiday away from his surroundings.

Until now this restriction could not be changed, even though DIN 18024 (German Industrial Standard) states that the construction and equipment of public buildings, streets, hotels, etc. have to meet the requirements of the handicapped.

The German handicapped experience a further restriction, if they want to go by bus, tram or any other public transport, except plane. Today wheelchair users must still sit in the luggage van when they go by train. The only thing left for the handicapped person, if he has a driving license and a car of his own, is to go by car.

Going to the theater or opera is rendered difficult by police regulations. Not more than six wheelchair users are admitted to a performance except with exceptional permission.

Barriers to Self-Determination in Education

Our handicapped patients presented another substantial chapter to me, in which self-determination is again subject to certain restrictions. Article 12 of the Basic Laws states that all Germans have the right of free choice of profession, and place of work and education. All work is equal in value and dignity for all social classes.

Well, how does it look for the disabled?

Attending school already raises difficulties. Not all federal states in the Federal Republic of Germany make available sufficient schooling facilities for the disabled, especially for the mentally retarded. Most of those children are not integrated in public schools, thus excluding them from the possibility of appropriate education. Consequently their quality of life is lowered considerably. Or they attend so-called "special schools."

Very often children with cerebral palsy cannot be integrated in the normal schools because teachers and the other students object to the sight of their handicap. There are only a few secondary schools meeting the requirements of the handicapped. In the city of Hamburg, there are two schools accessible to wheelchair users up to the final examination. Handicapped students are taken to school by special buses. There is no possibility of choice in this matter; otherwise the handicapped person would have to leave home and attend a boarding school far away.

Our institution makes use of a commercial school as a so-called "bedschool." This is why we are in a position to start relatively early with postgraduation even when there still does not exist sufficient ability to sit.

Our severely handicapped will, in most cases, have a commercial profession, or they will attend a university later on. In the city of Hamburg, technical studies such as electrotechnics, technical chemistry, as well as law, political economics, and science of industrial management are accessible to the disabled. Other studies can be selected in Hamburg, but wheelchair users have to be carried around because of architectural barriers. Recently our institute for social pedagogics had to be enlarged in order to meet the requirements of the handicapped after they had been on strike.

Other handicapped people are sent to institutions of vocational training by the Labor Office. Though they can choose a profession of their own preference, they have to pass a general test, an aptitude test, and a proving of skill. Afterwards, the Labor Office and social welfare discuss, together with the handicapped person, his further way of life. In conformity with basic law, the location of the institute of vocational training is determined by the insurance group.

However, there are objective limits, such as capacity and educational goal, to the right of being admitted to a place of vocational training. During the period of training, the handicapped person will have to comply with the fixed rules of vocational education.

Limitations in Vocational Autonomy

The next difficulty arises when trying to find a job. The law demands that an employer having at least 16 employees must hire the severely handicapped. If he fails to do so, the enterprise will have to pay a monthly penalty of DM 100 for every vacant post.

Very often this hiring requirement runs aground because of the lack of comprehension of the environment. Only in rare cases does the handicapped person get a job according to his liking, and a job change is out of the question for him.

Generally the handicapped are expected to have had a more qualified education and to be more correct in the execution of their duties, to take less time off for sickness or other reasons, and to have good social adaptation. The true accomplishment of the handicapped can only be correctly estimated in rare cases.

In Hamburg, I supply evaluations of handicapped persons regarding the limit of physical efficiency, peculiarities of action, range of motion, and needed aids. The corresponding place of work is also visited and evaluated.

A woman with cerebral palsy, now living in Sweden, has written to me that she is facing extreme difficulties while trying to realize her wish for an occupation. The working hours and the activity are determined by doctors and authorities without the cooperation of the handicapped person and are rarely revised. This determination seldom is in conformity with the wish of the individual and also not with the scale of offered jobs.

In the case of this woman, a vacancy was finally awarded to her. However, she was not given adequate work. In her report, she clearly gives expression to her wish for self-determination in a field of work and feels hampered by official measures.

Handicapped people who are not capable of working on the open market can attend the workshops for the handicapped. This occupation is voluntary. The disabled get wages, much lower than those in private enterprise. They must be able to produce 3 - 70% economically useful work. They are socially insured.

The workshop-employed handicapped do not have any possibility of pursuing activities of their own desire. They are tested on their abilities and then moved through an introductory and training step on to the production stage. We all know the repertoire of most workshops; they offer only little stimulation in the daily work.

The subject of the functions of the workshops ought to be developed. Nevertheless, one must state that through them the handicapped do get experience in efficiency and physical training. Through contact with other handicapped people and a working environment, the disabled come out of their isolation.

Limitations in Sexual Autonomy

Finally, I would like to mention a taboo in working with handicapped people. The handicapped have a vested right to sexuality like any other citizen. The White House Conference on Handicapped Individuals, 1977, expressively summarized this fact. A handicapped woman has the right of becoming pregnant and giving birth to a child. It is only for her to decide and she must not be forced to have an abortion.

Recently a woman with cerebral palsy gave birth to a child within our institution. Many had tried to persuade her to have an abortion,

though there was no doubt of her having a healthy baby. She was informed of all possible risks by doctors and then decided to bear to maturity. The child is illegitimate. According to the constitution, these children enjoy equal rights with those born legitimate. The law must do its utmost to grant the same chances to this child as to a child born in wedlock.

Due to the fact that the woman herself cannot take care of the baby, the welfare authority for the young decided to give the child to foster parents in order to have it brought up in a normal family. This happened with the consent of the board. This agreement resulted from the hopelessly constrained position that had been created by law and welfare. The sorrow and grief suffered by the handicapped has not been taken into consideration by the legislative authority.

All attempts to lodge mother and child together failed. Of course, it is important that the child should not imitate his mother's handicap, especially her dysarthric speech. However, feelings grown during pregnancy and birth cannot be destroyed. So, once a week this mother drives to meet her child and plays with him like a doll. Self-determination with a negative consequence.

Institutional Limitations and Opportunities

Ladies and Gentlemen, I have tried to depict a few points of daily routine in working with handicapped individuals in order to provoke some rational impulses. I am aware of the particular discussions about the value of institutions, in which self-determination needs to be restricted because the rights of the fellow-men have to be paid attention to.

Jakob Taubes says: "Institutions are the grand, preserving and devouring forms of order and fatalities outlasting us, which man enters with seeing eyes. They are menaced by power of the citizen of age." Edding says that human beings cannot live without institutions and that there does not exist any society not having created such. Portmann thinks man needs them in order to be less endangered.

Unfortunately, these institutions have the tendency to become ends in themselves and to be at odds with changing roles. Every generation will have to face and discuss this question repeatedly.

Where are our young handicapped to go, they who have a right to a decent life and an adequate education as well as a right to work and employment?

I have seen many housing projects for the handicapped fail, where total self-determination was practiced, because the inhabitants were more isolated than in an institution.

I maintain the opinion that we should create an integrated model which offers three possibilities: 1) nursing station, 2) temporary lodging, 3) service-house. In the second type, the disabled are to test themselves and to train themselves for living on their own. Only assistance in self-help is given to them. In the service-house, they will then live on their own and freely decide everything just as a non-handicapped citizen would.

A model institution of this kind already exists in Munich in the so-called "Pfennigparade." This institution takes care of patients suffering from respiratory paralysis and integrates them and their families in skyscraper dwelling units.

Conclusion

As a result from this workshop, I hope to give an impetus to politicians worldwide to reflect about self-determination for handicapped individuals in order to give them a comparatively equal quality of life.

Can self-determination of the handicapped be realized without any change of attitude and conscience of the nonhandicapped? It should be a fundamental task to make the nonhandicapped more sensitive to and, in a positive way, more conscious of the handicapped, and to create a spirit of positive partnership to realize self-determination for all citizens.

SOME REFLECTIONS OF A DISABLED PERSON ON THE SITUATION IN FRANCE

Bernard Lesigne, Administrator
Group for the Integration of the Physically Disabled, France

The Groupment pour l'Insertion des Handicapes Physiques (GIHP) has an overall membership (disabled and able-bodied) of 60,000 and has branches in 15 regions covering all the main French towns. Originally created in 1965 in the region of Nancy, its principal objective was and remains the transport of persons of reduced mobility.

The activity of the GIHP is not however limited to the transport of disabled people; it also takes part in certain ministerial committees set up by the Ministry of the Environment, such as the Council for the Housing and Transport of the Disabled. Moreover, it intervenes in the training and rehabilitation of the disabled, and on this account is concerned also with certain other ministries, such as Education, Labor, Industry, and Health.

Having made this point, it seems to me more important to report to members of this congress certain facts that affect the everyday lives of severely disabled people in France. However, in the interests of objectivity, I am duty bound to point out that I count myself as young in terms of disablement, my quadraplegia being only seven years old. And more especially I count myself as rich, having had the good idea in the first place of taking out insurance on my life. Thus, it is certain that my difficulties bear no relation to those suffered by such of my fellow-disabled as receive only a small disability pension. Nevertheless, I am as concerned as they are by the day-to-day problems of severe disablement, particularly because I encounter the same difficulties in daily life.

The first problem encountered, which arises immediately upon leaving the hospital, is that of housing. To convert a house, as I did, is expensive, and government aid is often difficult to obtain. As a result, it is often easier to look for alternative accommodation rather than bear the heavy cost of adaptation required to make the whole or part of the dwelling accessible. I should point out in this connection that nothing is done in France to help the disabled to attain home ownership, for they cannot even obtain a bank loan without paying an extra premimum--much to the joy of the insurance companies.

The second problem I would like to touch on concerns the possibility of working again. Quadraplegia does not mean incapacity; it is the limbs that are paralyzed, not the head. And yet, I don't know on what grounds, we are often considered to be beyond reclaim. Moreover, it is certain that nothing is done to improve the situation, since occupational therapy, which allows us to acquire more independence, is

barely recognized in France. The lack of formal status in this profession is cruelly felt.

The problem of securing a full-time attendant assumes considerable importance in France in view of the abdication of the authorities in this matter. Consider that the amount of state financial aid allows us to employ a cleaning woman for two hours a day. Is that the definition of a person whose help is necessary 24 out of 24 hours? In this connection I should point out that the government does not exonerate disabled persons from paying social security charges when they themselves employ someone on a remunerative basis.

The attitude of the world of the able-bodied often acts as a brake to rehabilitation. Why not teach school children that disablement is not a stigma, and that it can strike anybody at anytime? This would avoid certain surprising reactions, such as that of a teacher who required a little friend of my daughter to write several times in his exercise book, "I will not be cruel about the misfortunes of others." What had he done? Simply told my daughter that "her father wasn't the same as others." I think that this anecdote is fairly symptomatic of a world whose incomprehension in regard to us becomes disproportionate.

We don't wish to be dependent persons who are a charge on society. We wish to live a family life in surroundings adapted to our handicap.

THE RIGHT TO ALL TYPES OF INFORMATION

Karl-Erik Karlsson, President
National Association of the Deaf, Sweden

The first right to information is, of course, the right to know and understand what is going on in your family. Parents of deaf children should be informed that sign language is the only language their child can develop spontaneously in the way that hearing children develop their parents' language. The deaf child can never learn to hear, but hearing people around a deaf person can learn sign language and should get every possible support to do so. Otherwise, deaf children will be foreigners in their own homes.

In the beginning, most parents of handicapped children do not know anything about the handicap. Often it is a good idea to use grown-ups with the same handicap as the child's to give the parents information. Every country must have a system of informing parents about what they can do: how they should speak so that hard-of-hearing chilren can hear it, how they should describe things to blind children and let them feel what different things look like, how they should talk to their mentally retarded children and take them out to make available as many experiences as possible, and so forth. There is always a danger that parents may understimulate and underestimate their handicapped children and thus make them more handicapped.

Education and the Right to Information

For every handicapped child it is necessary that there be an early preschool and a good school with people and techniques that can help the child compensate for his/her handicap. But handicapped children have the right to be accepted as they are, and the practice should only be to make life easier for them in the long run. We as organizations must work hard on better attitudes towards the handicapped and better acceptance.

We deaf often notice that people don't like that we have a language of our own and that we want to go to schools for deaf people only. Our reason is that, as I said before, we cannot spontaneously develop any other language than a visual one. And to develop it fully, we must be surrounded by other people who use it. When we have a good start on sign language, we can learn the language of hearing people in our country as our first foreign language.

Only if we are educated in sign language do teaching and learning proceed with enough speed that we can manage to learn as much as hearing people. Then we can communicate on equal terms, through interpreters; read; write; and take part in public life.

Work and the Right to Information

All people must have the right to some kind of work. Different attitudes, different kinds of technical equipment, and personal assistance can make jobs possible for us to manage. We organizations for the handicapped have a big information mission in teaching the trade unions that the tempo and the pressure at work are a danger to everybody. At work, we must also have the social contacts and the information that for many people is what they get from their jobs in addition to money. We need all the information that is given at work, both formally and informally. Otherwise, in the long run, we don't function as we should.

In Sweden, the employer gets a sum from the Labor Department so that one of the other workers can spend some time assisting the handicapped person in activities such as reading letters to a blind person or answering telephone calls for a deaf person. A sign language interpreter can be asked to all formal work meetings to translate to deaf workers. The trade union paper can be recorded on tape for blind members. Less noise at work makes the place more pleasant for everyone and is necessary if the hard-of-hearing worker is to get information.

Safety and the Right to Information

In the streets, public places, and at work, all safety information must be presented in both visual and auditory formats. If a nuclear accident should happen in Sweden, we are supposed to listen to channel 3 on the radio until the danger is over. This is not a particularly good solution for deaf people! If you want to cross the street, you must wait until the light is green. This is not a particulary good solution for blind people. If you are in a railway station, you may hear on the loudspeaker that the train will come in to another platform. This is not a particulary good solution for hard-of-hearing people, because it is difficult to get good sound from those loudspeakers. If they had a TV monitor with the message written there, it would be easier for hard-of-hearing, deaf, and many others.

Mass Media and the Right to Information

Very different sources of information comprise the mass media: radio, TV, and newspapers. They are important because, at least in developed countries, they are a daily need just like our daily bread. If then, because of a handicap, you cannot access any of these, as deaf-blind people cannot, or can't hear, or can't see, or can't understand the words used, then you feel that you are not counted upon.

Television is supposed to be visual, but we deaf must have subtitles in order to follow it. The blind and many people with visual impairments can't read a daily newspaper. If the newspaper were taped, they could phone a special number and hear the newspaper read. Newspapers and other media use difficult language. Lots of people don't understand what is meant. If more work was done to make the message clear, it would be helpful to the mentally retarded and to deaf people who have sign language as their best language.

We deaf prefer information in our own language. In meetings, this can be done through an interpreter. In Sweden, the National Association of the Deaf has built a television studio and has started making programs using sign language. We put the programs on videotape and send them to the clubs for the deaf. In the future, we want every deaf person to get a video-player for his own house, free of cost, and to receive programs continually.

Community Participation

Organizations, trade unions, and political parties play an important role in the community. We organizations of handicapped people should keep in contact with them and make them support our opinions. We cannot by ourselves get the legislation that is necessary for change. As individuals, we handicapped should of course be members of organizations and parties we have sympathy with. We should always keep in mind that we have knowledge and experience that is useful to others. We need not only ask for information. We should also give information. Both are our right and duty.

THE RIGHT TO WORK: A POLITICAL ISSUE

Bengt Lindqvist, President
Central Committee of the Organizations of the Handicapped, Sweden

Everybody must feel that they have something to offer to others. To have a job or a meaningful role, to feel that one contributes to one's family and to one's society, is the right of every individual. We all know that today that right is denied the majority of disabled people in the world, not only in the developing countries but also in highly developed countries such as Canada and Sweden. There are many reasons for this, but I shall restrict myself to the treatment of a phenomenon that is all too seldom discussed in the international arena.

We have developed a narrow and short-term economic policy in our pursuit of profits and increasing economic growth that has sharpened the demands for efficiency and effectiveness. The competition for jobs intensifies and then the majority of the disabled have no chance. We disabled demand the same right to work as others, and we clearly can not accept the situation that exists today. Our societies must take forceful measures to achieve improvements.

Through work rehabilitation, we disabled can increase our capacity and, thereby, become more attractive to the labor market. There are shining examples of people throughout the world with severe disabilities who have gained and retained important positions in the labor market. They have achieved their positions through their own talents and through successful rehabilitation. This is good. We need them to make progress. But, for all that, we must not be led to believe that we have solved the problems of the disabled. It would be a fatal mistake to believe that we could solve problems for the many simply by referring to the success of the few.

To achieve progress, society must remove competition and, through various means, channel disabled people to working life. Our societies must initiate forceful programs with new laws, adapt places of work and the jobs themselves, and take other actions that can stimulate and, if necessary, force both public and private employers to employ disabled people.

The right to work is documented in the United Nations declaration on human rights. All member states are obliged to achieve this aim. Our societies are here faced with an important political decision. The right of the disabled to work can never be put into practice in a society based on free and unrestricted competition. It is true that the competitiveness of the disabled can be increased through various rehabilitative actions, but the effect of this will be marginal. The choice is whether to retain free competition or put the disabled person's right

to work into practice. This is a question for our politicians to answer, but it's a question that involves the disabled to a very great extent.

The right to work is fundamental for every human being. Therefore, our organizations must take measures that will actually lead to employment for the disabled, even if this means that we have to fight those who want to preserve free and unrestricted competition in jobs.

II.
Consumer Groups: A Description of Organizations & Functions

This chapter looks at how disabled people can work together through organizations to achieve common goals. Allan Simpson from Canada provides us with a comprehensive discussion about organizations of disabled people from a local to a national level. Ron Chandran-Dudley from Singapore explains the similarities between organizations of disabled people and organizations of people who are consumers of marketable goods. The remainder of the chapter looks at three different organizations' experiences: John Simkins from England describes how a group in his country was formed; Liam Maguire from Ireland describes the efforts of the trade unions to promote integration of handicapped people into society; and Linnéa Gardeström from Sweden describes the handicap council structure that exists in her country. Chapter 3 will highlight examples of the effects of the activities of these disability organizations.

CONSUMER GROUPS: THEIR ORGANIZATION AND FUNCTION*

Allan Simpson, Chairman
Coalition of Provincial Organizations of the Handicapped, Canada

The Historical Rationale

Modern society has demonstrated time and time again that full social/economic equality and acceptance for any disadvantaged target population can ultimately only be achieved by the target population itself. This requires philosophical unity of purpose, public visibility, direct representation, and dynamic political action, preferably of the constructive democratic brand.

The handicapped consumer movement is the grass roots democratic struggle of self-expression. The goal is to enable every handicapped person to achieve his/her maximum personal independence and full community integration according to the views and concerns of those citizens directly involved, and through the regular community/political decision-making processes and delivery systems.

One must examine why an individual citizen joins a consumer movement. By far, the largest number of citizens have joined a particular movement to press for adoption of basic civil and human rights legislation. For disabled citizens, application of civil rights legislation would mean accessible public services delivered via regular community or private delivery systems that serve the general population.

For some, the consumer movement has meant establishing an effective and distinctive organized voice as a balance to the rehabilitation industry in order to monitor historically over-protective, segregating policies and services. Consumers are beginning to question the high administrative budgets that often exist at the expense of aides, appliances, and other direct personal services desired by the consumer. The vested interests of some segregated workshops or professional counselling staffs are also questioned. Many consumers do not mean this in the negative sense. Simply put, every major government authority or industry needs a proper monitoring system of checks and balances.

Many see the consumer movement as the only effective means of neutralizing the damaging results of the charity ethic. Many consumers contend that sympathy fund raising results in low expectations of disabled people by the public. The fund raising may have created more damage than the benefit from the funds raised.

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*This paper is a condensed version of the original.

For others, the consumer movement's major purpose is public education to change public attitudes--to undo those unthinking barrier-creating attitudes of indifference, over-protection, or outright discimination.

And for still others, the local consumer group is a fellowship--a chance to enjoy common activities, concerns, and frustrations. This group often evolves into one with a combination of social-reaction programs and periodic social-action thrusts to meet various personal needs. This group's major involvement may result from an invitation by a local mayor, school, or service club to serve as a discussion panelist or an advisor to one of the town's planning committees. Little time would be spent in the analysis of legislation, underlying philosophy, social needs, or implementation tactics for long term systems or local issues.

Numerous local consumer action groups, particularly in rural or sparsely populated areas, have organized around one or two issues--particularly transportation or the removal of architectural barriers. ... The consumer group is constantly challanged with financial temptations to become a direct service provider and to allow the appropriate public authorities to avoid their full public mandates.

In the process of researching, sharing perspectives, forming policy directions, negotiating with civil servants, informing senior politicians, and utilizing the media, the disabled citizen learns about the consumer process and philosophy. He/she also learns how the social forces and political systems work. He/she learns there is a fairly standard pattern to most political decision-making processes and the potential effectiveness therein of an aggressive, responsible consumer group. It is a power that the group must use carefully with precise tactics--always mobilizing support; always firm, informed, and responsible; and always above reproach for any improper conduct. The democratic, constitutional rules of change are vehicles open to every citizen to learn and utilize.

Who Constitutes the Consumer Group

The heart and soul of the self-help consumer group is the individual citizen determined to take charge of his/her own lifestyle and decision making. He/she is prepared to recognize his or her own physical limitations and, at the same time, wishes to share in the responsibility of solving community problems faced by all disabled persons. The very nature of the self-help, consumer, monitoring process attracts individual members and leasers who recognize that all citizens, regardless of disability, education, employment status, etc., are capable in their own unique ways of growth and adaptation to new situations; that all citizens are worthy of respect, dignity, and access to basic public services.

While most Canadian consumer groups consist primarily of citizens with disabilities, more and more consumer groups are widening their membership categories to admit philosophically informed and supportive non-disabled associates, spouses, and others. The most active able-bodied members will naturally be spouses or other close family members living with the disabled person; they personally experience almost as much of the social barriers as the disabled person himself. A number of consumer groups also accept members who are able-bodied advocates of emotionally or mentally disabled persons. One consumer group accepts full voting able-bodied members if such a person is sponsored by a disabled member.

As in all political parties, social movements, women's groups, native groups, etc., there are at least two membership components. There is first the active participant who contributes his time and energies to insuring organizational coordination and administrative operation, and who also takes part in initial fundamental policy formations. An additional, and equally important, supportive associate member is one who wishes to endorse the fundamental policies and goals of the movement. This member often makes an equally effective contribution by working and influencing the credibility of the consumer philosophy at the community level in his everyday work.

The life and blood of the consumer group ultimately depend on the will and input of the individual grass roots members for the group's strength, credibility, and for its ever changing and increasing leadership needs.

Any real consumer group dependent only on a few members will soon "render itself impotent." Unless the general membership elects truly representative and effective leaders and takes strong united action to implement its policies at political levels, any consumer group will soon cease to exist.

What is the Essence of the Consumer Group

The true consumer group must offer an open, autonomous, and democratically shared forum for all disabled citizens.

The consumer group provides essential community checks and balances through citizen responsibility. It also influences new, innovative ways of solving long-term needs, particularly those faced by severely disabled citizens.

The consumer group must be a stable but ever growing and visible force. It must also be recognized as a healthy and natural extension

of and beyond the rehabilitation process. This self-determination and direct involvement in community affairs, and the public and political exposure (which no professional rehabilitation counselling system could ever provide) should be a welcome self-development process.

Community experience through involvement in consumer groups has demonstrated that real personal growth and learning takes place ultimately only on the job, or on the line in the actual real work environment.

What the consumer movement demonstrates is that "the very means of solving a problem is as important as the solutions to the problem itself." So few organizations in society realize that each problem-solving and sharing process is and should be a vital learning experience for every individual involved.

Every individual, regardless of mental skills or social limitations, must always be encouraged and permitted to experience maximum self-direction and community experience to maximize his or her understanding of the issues and the availability of services or resources necessary to solve their needs, e.g., how to apply for his own home care assistance, a powered wheelchair, modifications for a house ramp, etc., rather than relying on an agency counsellor to do it for him.

Consumer Organizational Models

In any discussion of consumer organizations, the reader must first understand that the consumer groups or coalitions are modelled after and parallel to major political structures. This parallelism is necessary to provide an effective consumer balance to the existing political/community authorities.

Hence, the local consumer group structure, its membership, and its essential issues usually parallel those of the existing local municipal or county government and service systems. Local members, as citizens of a province or state, may also belong to a larger provincial group or coalition structure to deal directly with issues under provincial or state jurisdiction and with provincial or state authorities. Cross-disability coalitions are emerging as the most effective provincial coordinating action structures for individual members, numerous local consumer groups, and uni-disability advocacy associations. Members are also citizens of a country, and as such, are encouraged either as individuals or as provincial coalition delegates to become involved in national issues through their national coalitions.

It is quite common for an individual to be a member of groups at all three levels, but he/she usually allocates his/her priority, energy, and efforts to one of these organizational levels.

While many of the uni-disability consumer associations have spread to the local level from a national organizational base, most of the cross-disability consumer groups were initiated at the provincial or state levels in North America. These regional groups soon realized that their effectiveness was limited; they could not achieve the necessary results without a strong national voice. Thus, coalition of existing regional groups, national uni-disability consumer associations, etc. has become the most effective way of mobilizing the movement nationally.

The Formal Organizational Consumer Structure

The formal organizational model usually consists of a traditional structure that is highly centralized and includes policy conferences, an elected board, a head office, and staff. The membership consists of paid-up active members, individual associates, and other affiliated members. The annual conference and general meetings establish basic membership policy.

Selected board/council representatives and appointed executive officers are authorized to coordinate the members' policies and resources and to implement the detailed strategies for specific approaches at the political level. Members may be directly involved through one or more of the various research committees or through specific action subgroups.

Administrative staff and office assistants provide essential research and coordination of information, fund raising, and organizational support systems. Because these structures usually operate under well-established procedures, they do provide basic democratic decision-making experience. However, they tend to over-rely on the leadership of the elected board or council for implementation.

The Informal Action Group Structure

Under the dynamic informal action group model, all members are usually encouraged to unite and concentrate on one or two fundamental, far-reaching, cross-disability issues at a time. At a major open assembly or conference, a basic issue or goal, documented with appropriate research, will be presented for initial adoption. From the time of adoption, all efforts are directed at involving the total membership in planning and implementing detailed strategies. Tasks are assigned by the assembly to various groups to be carried out between the time of the current meeting and the next meeting, perhaps one or two months hence. These particular assigned functions may include the following:

1. Draft a brief for presentation of all relevant facts and arguments on a specific issue.

2. Secure a date and time for meeting with governmental officials and members of the elected house.
3. Establish a newsletter and update system to disseminate information to all members on the specific issue.
4. Draft press releases and letters to editors in order to inform the public.
5. Arrange for news media, TV, newspaper interviews and feature articles to insure that a constructive image of the needs and benefits for the whole community are understood.
6. Raise funds for travel, printing, research staff, office space, etc.
7. Secure allied group endorsements and public understanding for the specific issue.
8. Draft model legislation for review at a future meeting, in order to have effective models to present to government.
9. Establish plans to assist with transportation/volunteer support for those who may require such.
10. Prepare for next action planning meeting and insure assigned tasks are on target for that particular date.

This informal process may have to be coordinated by a few individuals in its early stages. Through total involvement, sharing, and internal accountability processes, this process soon develops a broad group of well-informed leaders throughout the entire membership. ...

Long-term organizational skill and volunteer satisfaction can be achieved only if clear job descriptions, time frames, and general awareness of everyone's function are clearly articulated and documented at the end of each meeting. This can be a highly effective and motivating form of membership involvement. The reason is that the membership is working together and understands that by putting in a highly concentrated effort, specific objectives can be accomplished within a relatively limited time frame.

In reality, it is quite possible that the successful consumer group will utilize a combination of the two structures presented above.

The National Coalition

The national level should consist of a well-structured coalition of either provincial coalitions or a balance of provincial/state and national uni-disability consumer groups, all united for specific common goals.

The purpose of national coalition, very clearly outlined in the report, Coalition Building, by the American Coalition of Citizens with

Disabilities (ACCD) is: to concentrate on major national civil/human rights legislation and legislation to cover the essential policy direction and funding needs of basic community services in the areas of transportation, housing, education, employment, social security, appropriate rehabilitation services, independent living support systems, and so on. The essence of a national coalition is to establish working models, research documentation, and leadership development programs that will benefit the consumer movement across the entire country at the provincial/state and/or local levels.

The Provincial Coalition

At the provincial level there are usually a multitude of politically active organizations consisting of both local-issue cross-disability coalitions and uni-disability consumer and semi-service associations. The need for coalition building is obvious. The uni-disability organizations usually concentrate on issues regarding their specific disability needs.

The provincial cross-disability coalition should attempt to coordinate all regional members and groups committed to consumer group functions. The provincial coalition is the most effective and important strategy coordinating arm of the consumer movement. It has the geographic and jurisdictional scope to fully involve individual members on major concerns in the region. It has the means to mobilize local and other very small consumer groups in the rural and town areas throughout the region.

The Local Consumer Group

The local group is the most important membership development and implementation structure in the consumer coalition movement. It is at this level that actual federal or provincial legislation is converted into practical community service delivery systems. As such, it is the local group that must conduct the specific monitoring and negotiating with the community boards and the political authorities responsible for delivering specific public services. Often the local group is confronted with the challenge of either establishing its' own demonstration project, just to clarify how a particular service can be provided, or conducting a very extensive lobbying campaign.

Other important functions of the local group are to inform and involve the local membership in monitoring the application of legislation for the development of integrated public services. They can also act to see that qualified consumers are elected or appointed to various local community boards and authorities, such as school boards, hospital

boards, community transportation boards, employment advisory commissions, and recreation commissions to insure consumer input and technical skill development. This community involvement is also an excellent public education service that can demonstrate the leadership capacity of the disabled community.

Consumer Groups in the Canadian Context

The reader must understand that the split in Canadian federal/provincial political jurisdictions does not offer many of the advantages available in other countries--advantages that are necessary in order to bring about uniform national services, legislation, and attitudes conducive to the needs of all disabled citizens.

1. Canada has no civil rights legislation providing a legal foundation of insured direction and protection from which to build a citizen's essential services and entitlements.

2. Canadian human rights legislation, which currently provides limited protection from discrimination due to a physical disability, is just now being formulated in Canada. Provincial human rights legislation in four provinces is limited by its inconsistencies and narrow coverage, and cautious commission tribunals make them almost ineffective.

3. The division of federal/provincial social service jurisdictions create a serious implementation dilemma for all Canadians. The federal government has the basic financial resources and responsibility for Canadian unity, commerce, and national security. The provincial authorities have total jurisdiction over the delivery of social services, education, and housing, thus leading to ten different standards and approaches to the basic community living needs of Canadians.

4. The bilingual nature of this country requires that basic consumer communications serve the needs of the visually handicapped, the hard-of-hearing, and the nonverbal disabled citizen in both the French and English communities. We are pleased to note that Canada's consumer coalition, COPOH, has developed specific policies to insure that basic translation of services is offered in all national conferences, seminars, and reports.

5. The charity ethic is deeply rooted in Canadian society.

6. Public education about the basic needs of disabled citizens has been almost entirely generated as a result of sympathy-based fund raising drives.

Coalition Building--An Essential Part of the Consumer Movement

Unifying all national and regional consumer groups and those advocacy service organizations truly supportive of the consumer monitoring, decision-making, leadership philosophy, will be the central challenge in the 1980s.

The excellent report, Coalition Building, published by ACCD should be read by all concerned individuals, especially those involved in building the consumer movement.

Membership Motivation and Involvement

Citizenship involvement in the political process in Canada is not a natural experience in the educational process. Until very recently, few disabled persons in Canada have ever been involved in local civic affairs, service club boards, school councils, church boards, or political office. Hence, few disabled people in Canada have been aware of how the political/bureaucratic process can be made to work for a community need. Additional efforts were and still are required in order to provide community leadership experience for the disabled person. It is essential for consumers to gain an appreciation of how group dynamics, consensus building, group sharing, and internal decision-making procedures are evolved and implemented at the political/bureaucratic levels. The individual must learn how the political system works, how legislators are presented with new information and concepts, and how these are then turned into specific legislation and detailed community services.

First, the consumer group must understand how internal motivational group dynamics operate. Motivation of the membership begins with understanding why individual members have joined and what particular goals and aspirations they are looking for. For example, it is unfair to let the individual member assume that he/she is joining a social club for recreational activities.

Policy conflicts and human misunderstandings will inevitably occur. When this happens, it is very important to encourage all members to openly examine the background of an issue to clarify any misunderstanding of the central questions, separate out any personality conflicts, and then arrive at a consensus of opinion or majority vote. It must also be made very clear, and continuously reinforced, that differences of opinion will inevitably occur as a natural part of any organization. But the democratic process must clearly outline to the membership how they can become involved in reviewing or instituting a second look at unresolved issues.

7. A few large national rehabilitation agencies dominate almost every aspect of both rehabilitation treatment and community living services required by disabled citizens.

The Canadian Consumer Coalition

The Canadian Coalition of Provincial Organizations of the Handicapped (COPOH), is currently structured as a national coalition of provincial coordinating member coalitions. Most of the organizational components are equivalent to ACCD.

Eight provincial coordinating members and associate members from two provinces in the process of forming provincial coalitions constitute the administrative base of COPOH. These provincial coordinating members are responsible for coordinating the views, policies, and delegates of all interested consumer members in their regions. Each provincial coordinating member appoints two representatives and two alternates to the national council.

The national council elects all executive officers and is responsible for establishing and implementing basic policies in accordance with the principles, resolutions, and directions of the national delegate assembly.

Open national conferences provide a forum for establishing basic policy direction. They are open to all provincially-sponsored voting delegates and to any other individuals who wish to present specific national issues or recommendations. National delegate assemblies are also held in conjunction with the open national conferences and provide a population-balanced delegate system to ratify the resolutions presented by the open conference delegates.

The chairman of the national council serves as the senior spokesman of the organization and insures coordination of national policy decisions.

The staff and central office, under the national coordinator, provide for research and communication to the members. They coordinate the grant applications necessary for the operations of the organization. The national coordinator assists the executive officers and committee chairmen in communicating the policy resolutions of the membership to appropriate federal authorities. He is also available to assist provincial organizations in strengthening their consumer structures and influences.

Group decisions must not prevent the individual or associate group of members from openly and honestly disagreeing with the majority's decision and constructively suggesting alternative solutions to the appropriate authorities as part of their minority viewpoint responsibilities.

A second motivational method is to work in small groups explaining, and sharing--each learning step-by-step and moving only as fast as the average member can understand the process.

Regular informative communication is essential to maintaining any membership.

Fundamental Operating Principles

The following operating policies outline a few of the basic principles adopted by a number of consumer groups. Not necessarily in any order of priority, these operating principles include the need to:

1. Maintain an open membership and insure that all disabled citizens are invited to participate in open assembly conferences as a basic citizenship right and responsibility.

2. Provide regular, dependable, communication to the active and concerned non-active members, being particularly sensitive to the needs of those with language or communication handicaps.

3. Establish a solid democratic constitutional base, clear job descriptions, and clear operating principles to motivate members through maximum involvement in all fundamental internal policy decisions.

4. Be autonomous and based on maximum self-help, i.e., the group should not be controlled or influenced by any large external force other than the members.

5. Have general funding accepted only from philosophically supportive sources, and without any strings attached. (Few true consumer groups will accept funds from service agencies that have raised their public funds through the traditional charity sympathy appeals.)

6. Coordinate the consumers' views and concerns, and to insure their maximum involvement in all related community policies and decision-making systems. (This is a primary purpose; consumer groups cannot be a federation of recreation or

social clubs, because their structures and purposes are inappropriate for the community monitoring/political influencing functions.)

7. Insure and promote the concept of services being provided only by the appropriate community delivery systems that serve the whole community.

8. Have all consumer action projects, in addition to initial goals, strive for:

   (a) the building of consumer cross-disability cooperation, experience, and trust;

   (b) the establishment of greater public/political credibility for the consumer group as a firm, responsible force serving the whole society.

9. Avoid becoming a professional or permanent service delivery organization other than in providing information or consumer research data to members and the general public.

10. Avoid owning a direct service or establishing a service demonstration project. First, thoroughly investigate all established community service authorities. If there are no established services, then sponsor a community board with political/community representation and a majority representation by consumers.

11. Avoid the image or the temptation of representing disabled people as wanting segregated services or special favorable treatment. Where necessary, clarify that only essential supportive systems with appropriate modifications are requested, and that these services are requested through the regular community delivery systems--"specialized services if necessary, but not necessarily specialized services."

12. Research all relevant facts of an issue before presenting alternative action plans to the members. Include full disclosure of the advantages and disadvantages of each option presented.

13. Avoid staff domination by insuring that staff are committed to providing a strong information and administrative base. They must also be prepared to build cooperation and communication and to avoid taking sides on any outstanding internal political issue.

14. Develop a strong, in-depth working relationship with the media, always using it factually and constructively.

15. Develop regular communication and working relationships with at least three major and natural allies of the consumer movement:

    (a) the union movement

    (b) the business community, e.g., the Chamber of Commerce

    (c) the inter-faith community, e.g., the Council of Churches.

16. Avoid communicating with your government minister through permanently established handicapped advisory committees appointed by government to coordinate and represent the general views of disabled citizens. These committees are a direct contradiction and challenge to the right of people to represent themselves through their own autonomous consumer groups. Establish a clear policy understanding, internally, that only consumer groups, through their policies and elected representatives, have legitimate authority to speak and negotiate their own concerns. Individuals appointed to government advisory committees are answerable only to themselves and the minister making the appointment.

Overcoming External Resistance

The consumer movement has experienced tremendous resistance, especially from the rehabilitation industry's bureaucratic levels. Each of these challenges has a number of alternative solutions.

Paternalistic resistance. Many of the underlying problems faced by consumer groups are deeply rooted in all forms of paternalism from individuals or groups that want to constantly over-protect. First, past services must be appreciated. Then plan an extensive series of meetings and reorientation events demonstrating how, with appropriate support, disabled individuals accomplish more if allowed to develop their own solutions. The paternalistic groups and individuals will eventually begin to realize how the consumer risk-taking process actually enables the individual to become self-reliant.

The public prestige seeker. There are those helping-hands who volunteer their names and often funds in order to obtain public recog-

nition. These individuals can be informed of the real value of a direct working relationship with and support for the leadership of the consumer movement. Reorientate them to understand that they will be serving their own particular public goals and needs if their relationship with the disabled is on a one-to-one basis.

Vested interest resistance. This resistance is often generated by those who are directly involved in staff positions of traditional rehabilitation service agencies. It is almost impossible to overcome this natural, self-protective resistance. If at all possible, convince these staff members that there will always be a need for qualified service providers and counsellors for those who really need professional counselling. Having recognized this need, the consumer group must continue to inform the professional why non-rehabilitation community services are required through appropriate general community delivery systems and independent living centers.

Low expectation. This is one of the most deep-seated resistance forces. This resistance is best countered by patient firmness, always succeeding with small specific projects. Through self-expression, creativity, and risk-taking, each success proves the underlying capacities of all human beings.

Internal Growing Pains

Consumer misunderstanding. Often a number of new or uninvolved members express a lack of understanding about the purposes and/or processes of group action. They may lack a sense of satisfaction that can be achieved by working for a common goal, or in planning and then knowing how to go about solving a need. This group must set one specific and reachable goal as its target. Motivation can be achieved through group sharing, learning, and goal setting.

Divisive group patterns and unclear goals. This problem may indicate the need for a membership review conference to examine in thorough detail the priority goals, the rationale of how the group works, why and where the constitution needs to be changed, and so forth. Also the group problem-solving processes need re-examination. Internal administrative decision-making may also discourage the general membership if it is not conducted in a democratic manner. Periodic open membership review sessions may help resolve mistrust.

Organizational administrative inexperience. Until recently, few consumers, particularly in the Canadian context, had extensive organizational experience with community groups. Organizational and administrative experience gained through the consumer movement has enabled many disabled individuals to apply their skills in other community or-

ganizations, including new business structures established by consumers. Therefore, it is extremely important that every project a consumer group undertakes must include the maximum amount of work-learning experience.

Shortage of leadership. This basically means that experienced leaders are not accepting their responsibility to share their organizational talents with those less experienced. It may also mean that the group is involved with and divided by too many issues or projects at any one time. A review of priorities may reveal the need to concentrate all efforts in one or two directions. The issue or consumer action project serving the greatest number of members over the long run is that which provides legislative support for basic rights and public service needs; e.g., human rights, public transportation, education, development of meaningful employment, etc.

Shortage of funds. Many consumer groups have existed at the local level through volunteers and donated office supplies. In order to provide for the necessary central research staff and internal communications, the consumer network requires sufficient funds for conferences, travel, and hiring of appropriate handicapped/nonhandicapped staff. Funds are essential to involving both experienced and inexperienced handicapped people in organizational consumer development, community monitoring, and advisory input. The historically negative public education generated by charity-sympathy fund raising on the part of the traditional volunteer welfare and service agencies must be avoided at all costs.

Consumer groups must develop their own firm, positive, internal public relations guidelines for all fund-raising endeavors. In addition to donations from members and supporters, as well as from community foundations, many consumer groups have established fund-raising projects that involve offering appropriate goods and services to the community in return for a reasonable dollar payment. The United Appeal or the United Way campaigns in various countries appear to have improved their public fund-raising image to one of serving the whole community. This philosophy allows consumer groups to consider approaching the United Way for a certain proportion of their funding.

Some advanced thinking is seen in governments that have specific policies and/or legislation to provide core funding support for citizenship development of specific disadvantage groups, e.g., women, native populations, the disabled, national self-help groups. Governments also wish to contract directly with consumer groups to research or advise their departments on specific areas of need or opinions of a target population. These contracts also provide invaluable employment and research experience for disabled citizens. It also helps consumer groups realistically understand the political/bureaucratic systems and their limitations. They soon learn the consumer movement has a valid voice

and henceforth will not be left out of society's decision-making responsibilities.

Relationships with the Community

The consumer group is not an island unto itself. It must not fall into the trap of becoming a social circle that is an alternative to community integration. Rather, reaching out, it must be a sharing part of the community, always bridging gaps to enhance consumer involvement and recognition.

Traditional rehabilitation agencies seldom include disabled board members. Where disabled people were accepted on boards, few had any particular experience or background in the consumer movement. It is apparent that individual consumers should be encouraged to run for elected office on various rehabilitation service organizations. If sufficient numbers are elected, it should insure that well-established consumer policies and principles are advocated. They can also assist these agencies in their policy evaluation and long-range planning. This assistance is extremely important to avoid duplication or misunderstanding about the limited roles of the rehabilitation agencies versus the independent living centers versus regular community delivery systems mandated to serve all members of society.

With the evolution of the consumer movement into a dynamic and recognized political force, it is now quite common for political ministers to negotiate directly with consumer groups. This recognition motivates department officials to contract directly with consumer groups to obtain consumer experience and specific data as a base for new policy proposals to be shared with the consumer group before establishing a firm direction. The collection of information and research data is an accepted and valid component of the consumer movement's indirect responsibilities. It must be clearly noted that today, most consumer groups insist that "quality research work demands a quality dollar" as well as recognition of the value of consumer research.

Government funded research projects should in no way imply that a consumer group is working for or endorses any political party. Most consumer groups take an emphatic policy stand to remain nonpartisan and above party politics. It is best to lobby all parties for specific issues and to seek uniform endorsement of established consumer policies. In this way the consumers can belong to political parties as their conscience and viewpoints dictate. They can also utilize these links with their personal party affiliations as a vehicle for advancing specific consumer policy issues.

Future Challenges Facing the Consumer Movement

History demonstrates that most citizen movements either become a part of the establishment or fade away to make room for new movements. It is therefore quite conceivable that parts of the consumer movement will be institutionalized and other aspects will fade in the future. But what will be important is to insure the permanent provision of an autonomous, open, disabled persons' forum.

The most natural challenge will come from the large, established, coordinating, umbrella agencies in rehabilitation that will attempt to capture the consumer base through funding. While these financial support offers may be very sincere and magnanimous, they could, if accepted, seriously undermine the autonomous consumer group. Over-dependence on the very organizations that require monitoring would erode the freedom of objective evaluation. It could also undermine the key self-help, development role that is such an integral and important part of the consumer growth process.

Should consumers accept public services from inappropriate health or rehabilitation agency providers? Is it better to take a stand and reject an inappropriate service system as a means of demonstrating their insistence on recognition by the regular public delivery systems?

Does the consumer movement have the right to deny the individual volunteer his or her right to give and to feel good about giving? As the consumer movement moves closer and closer to insured public services, does it inevitably mean the consumer does not wish to be dependent upon the volunteer charity dollar? Does the consumer movement realize how the insured service funding threatens the sense of self-importance and the feeling of pride that is generated by the volunteer giver? Does the consumer group want to destroy all charity fund raising, redirect it, or promote the concept of volunteer working partnerships without direct fund-raising appeals?

How shall we face the challenge of the growing sheltered and segregated workshop industry? These industries use the image of training as an excuse for avoiding minimum wage standards for its employees while producing real manufacturing goods for commercial government contracts.

Should the consumer movement accept the premise that equal work should pay equal dollars or that it should pay a minimum income as required by all individuals in order to exist? For those unable to hold full-time, gainful employment, would it not be better to transfer their social security income payments to an employment system, even if part-time, to insure that the dollars flow through the normal employer/employee relationships? Would this transfer system then entitle the individual to insurance benefits, pension benefits, unemployment insurance,

and numerous other social community services, such as credit ratings, and that all important feeling of self-worth and dignity?

Public indifference and misunderstanding will continue to be a major challenge to the consumer movement. It is important for each consumer to understand that the average citizen without a disability cannot be intimately sensitive to the needs of disabled persons or even aware of the barriers established by unthinking bureaucrats or political representatives. The consumer movement must propose constructive, natural ways for all citizens to become aware of each person's unique abilities and personal needs. The answer is surely in being visible and active in all public forums. This also means assuming leadership roles, serving at the town fair or a school board meeting, and utilizing a shopping center, theater, the playground or going on a fishing trip with neighbors. Only by meeting fellow citizens on a person-to-person basis will true acceptance and integration occur. This process must begin at the junior school levels. The greater the number of handicapped people who can participate in classrooms the greater the natural interaction and acceptance.

CONSUMER GROUPS: THEIR ORGANIZATION AND FUNCTION

Ron Chandran-Dudley, Vice President
Rehabilitation International, Singapore

Modern man and woman have become very highly consumer-oriented individuals. To a greater or lesser degree, all of us have developed a variety of needs, be they for merchandise or for services. In any community there are individuals who depend on specialized goods and services for some part of their lives, while others will have to depend on these for all of their lives. There are also those who are purely consumers, while others are consumers as well as providers or manufacturers.

It somehow seems to me that it is a historical *fait accompli* that when there are dichotomous and juxtaposed circumstances or points of view, these give rise to a situation of conflict. It is this aspect of the situation of conflict that I would like to deal with in this paper and, in particular, with the consumer groups that have highly specialized service and merchandise needs--I mean, the disabled among us.

Definitions

In 1893 in the United Kingdom, the law called the Sale of Goods Act was codified. The term "goods" is defined as "all chattels personal other than things in action and money." Here, a contract for sale of goods should be differentiated from a contract for work and labor. From the above, it then follows that if a contract is one for work and labor, then the terms implied by the Sale of Goods Act (i.e., that goods supplied are of good quality and reasonably fit for the purpose for which they are required) do not apply.

However, the House of Lords of the British Parliament maintained that in the case of a contract to do work and to supply materials, two warranties may be implied in respect to the materials supplied. First, a warranty of their reasonable suitability for the purpose, and second, a warranty of their good quality, particularly against any potential defects. Where the materials for a particular project have been chosen by the consumer, then the suitability requirement is not implied. However, the quality of the materials, unless otherwise stated, is implied.

Two other points need to be born in mind while discussing consumer needs--merchantable quality, and seller's skill.

Goods are said to be of merchantable quality if they are "in such an actual state that a buyer fully acquainted with the facts and therefore knowing what hidden defects exist and not being limited to their

apparent condition would buy them without abatement of the price obtainable for such goods if in reasonable sound order and condition and without special terms."

Reliance on the seller's skill or judgement need not be total or exclusive, but it must be substantial and effective. However, there must still be some reliance on the skill and judgement of the manufacturer who has to comply with the plan and specifications in respect to the fitness of the product. "Reliance on the seller's skill and judgement will usually arise by implication from the circumstances, and if the particular purpose for which the buyer requires the goods are either obvious or the buyer's special purpose is made known to the seller, then in the absence of anything to the contrary, reliance on the seller's skill and judgement is implied." An example of this is the purchase of a vehicle, duly modified for disabled drivers or a motorized wheelchair or any other technical aid or architectural modification for the disabled.

It is essential to know that the disabled consumer, just as his able-bodied counterpart, can have recourse to the law and possible compensation if the retailer sells goods obtained from a manufacturer that, owing to some latent defect, cause injury to the ultimate buyer or consumer. Damages with regard to defects in aids can be claimed from the retailer in contract and, in certain circumstances, from the manufacturer in tort.

The Disabled as Consumers

If I may be allowed some license, I would like to draw parallels between organizations for the manufacture of goods and organizations for the welfare of the disabled. Both these organizations are involved in "production." Robert Scott, in his published thesis, talks in terms of "the making of blind men." In a sense it can be argued that agencies for the disabled tend to bend their clients into the agency product. These clients are then referred to as "cooperative clients" as opposed to those who do not want to and cannot fit into the mold and are then, like the manufacturer with his nonconforming product, labelled "rejects."

Both these organizations also serve a clientele that can be referred to as consumers of the goods and services of these establishments. Therefore, as consumers, their interests must be safeguarded. Manufacturers and voluntary agencies for the disabled must maintain certain organizational and service standards if they are to satisfactorily meet the ever-increasing demands for quality products and quality service.

As mentioned earlier, whenever there is a dichotomy, a situation of conflict could arise. Such is the case between manufacturers and their consumers and between voluntary agencies and their consumers. One suggested way to resolve this potential situation of conflict is to allow the consumers to participate at the policy level as well as at other levels of the organizational hierarchy. Another alternative is to have the consumers participate in the ownership of the organization, i.e., set up more cooperatives in the industrial and voluntary sectors. A third alternative is to set up powerful, dynamic, and effective consumer organizations nationally and internationally to serve as watchdogs, advisers, and providers of feedback to manufacturers and voluntary agencies.

Some Functions of Consumer Organizations

Disabled individuals in the community are consumers of specialized goods and services in addition to being consumers of regular commodities and services. Their needs are therefore unique, and agencies that set themselves up to serve this group of consumers have to be, of necessity, highly skilled in their service delivery. Listed below are some of the functions that are imperative for the effective working of consumer organizations of the disabled:

1. They must protect the rights of the disabled and work towards the formulation, wherever necessary, and the enforcement of consumer protection laws.

2. They must insure that their voices are heard clearly on matters concerning health and safety, education and welfare, cultural and architectural barriers, economic well-being, legislation, psycho-social concerns, and transportation.

3. They must represent their groups forcefully before government and statutory bodies, nongovernment agencies, and the private sector.

4. They must study common problems, such as stabilization, reasonableness, and uniformity of the prices of technical aids for the disabled, and the costs of transportation by land and air for the disabled and their aides.

5. They must eradicate unethical trade practices, particularly in reference to medical, para-medical, and pharmaceutical products.

6. They must encourage and activate the formation of disabled consumers' and producers' cooperatives.

7. They should encourage greater cooperation and dialogue between consumers and the staff and officials of voluntary agencies. (Because of the alienation of consumers from the voluntary agency hierarchy, there is a paucity of dialogue between them at this point.)

8. They must see that adequate standards are maintained by the agency serving the disabled. Machinery for the accreditation of services for the disabled should be set up where none exists. Standards of academic, socio-cultural, vocational, and other services must be maintained at the same level as is prevalent in the rest of the country.

A Model of Organizational Functioning

In discussing the design of organizations, several factors have to be considered, not least among these being the style of supervision--whether, for example, it is participatory or autocratic. Such a model should also take into account the values and goals of those at the helm of affairs in the organization. These are more than likely to have far-reaching implications for the design of the organization.

Organizations consist of people. Human motivation, perception, and attitudes greatly affect the functioning of organizations. The influences that are brought to bear upon an organization will depend upon whether or not the members are motivated or alienated, cooperative or obstructive, creative and innovative or staid and nonprogressive. Thus, the dimensions of human behavior should also be included in a model of organizational functioning.

Economists have argued that the price and production of the commodities of a firm will influence the demand and supply in the market. This is true for industrial plants and their consumers; it can also be true for the consumers of services of voluntary agencies and sheltered workshops. Sociologists have emphasized the importance of the legitimacy of the organization in the society in which it operates. Functionally then, economic as well as cultural aspects are necessary for an organization's existence. According to contingency and systems theorists, the external environment has its influence too in the shaping of the organizations structure and operations.

The level of sophistication and the standards of an organization, voluntary or otherwise, will depend on its quality of performance with regard to its goals and objectives. The efficiency in operating with regard to economy of scale is dependent upon the size of the agency and its age and experience.

Description of the Model

According to *The Design of Organizations* by Pradip N. Khandwalla, there are five classes of variables that describe a model of organization, namely 1) situational, 2) strategic, 3) structural, 4) behavioral, and 5) performance.

The *situational* or contextual variables cover external, environmental, and what might be called demographic variables. They represent the situation or context within which an organization functions. They are the primary source of constraints, contingencies, opportunities, and threats faced by the organization as a unit. In the long run, they shape the inner workings of the organization.

The situational or contextual variables that can be known as demographic variables represent "size, age, nature of ownership (or who the principal beneficiaries of the organization are), and the nature of output (products versus services)." Although these variables have great influence on the organizational structure, they can only be changed with great difficulty, by managerial action.

The *strategic* variables consist of the organization's goals, top management ideology and style, and the organizational strategy for survival and growth. In management literature they are called "policy variables." These variables can be manipulated to a point and changes in them will have deep and long-term consequences for the organization concerned.

The *structural* variables, as the name implies, form the framework of the organization. They formulate the durable relationships and long-term working arrangements. The superstructure of the organization, the way people are grouped into departments in the organization, is one dimension of structure. The infrastructure of the organization, the system of controls and authority relationships, staff functions, formalization of communications, various performance programs, and operating procedures, is another dimension. The different functions categorized under the superstructure and the infrastructure together include differentiation and reduction of uncertainty, coordination, and integration of activities.

The *behavioral* variables describe the actual behavior that takes place in organizations as their members and staff struggle to meet their own needs as well as the organization's demands on them. Organizations vary in the degree of cooperation and conflict that exists within them, so also do the levels of morale and job satisfaction. The resistance or encouragement to change or innovation varies from organization to organization. Some members reveal open alienation while others reveal motivated behavior.

Performance variables are, or should be, constantly evaluated by the management hierarchy within the organization and are often evaluated by interested parties outside. The more common performance variables are: efficiency (profitability), rate of growth (positive or negative), and degree of market or community acceptance. Organizational performance is usually assessed in reference to some standards. Past performance of the organization and the performance of comparable organizations are the usual sources of these standards.

It is also plausible that a highly motivated membership, which is creative and innovative, could develop an organization with superior performance, while an alienated membership, which is regressive, non-innovative, and riddled with conflict may give rise to an organization with low-level performance.

In the present context, a consumer organization functioning with a combination of a dynamic membership environment, a risk-taking, top-level executive philosophy, a flexible organizational structure with a strong information and control system, and high levels of motivation and readiness to accept innovation on the part of the organizational rank and file, may more surely lead to superior organizational performance than any of the foregoing in isolation.

Change in the physical environment, as in the behavioral patterns of members, can only be brought about through long-term planning and action.

Management's plea to quarreling groups to start cooperating has little effect. Unless one is a Ghandi or a Mao Tse-tung, these pleas to work harder, to cooperate, and to innovate will be in vain and remain unheeded. On the other hand, objectives can be reformulated and goals reset, management styles and philosophy can be reconditioned, strategy can be modified, and structural changes such as decentralization and reorganization can be wrought more easily.

Conclusion

In this paper, I have drawn together several elements from the industrial and commercial sectors and attempted to find analogies in the agencies purporting to serve the interests of the disabled. Just as the consumer of the manufactured commodity has formulated legislation for the preservation and protection of his interests, so also have many disabled persons who are consumers of service delivery agencies formulated and established organizations for the protection of their interests.

There are many obvious differences in both these kinds of institutions, the industrial and the voluntary agency organizations. One outstanding difference is that the voluntary agencies receive the majority of their revenue from the members of the public for what, in effect, could be promissory notes, or, put in another way, raising money for future stock. Often, in many countries, these goods and services are never seen by either the clients or the benefactors. If services are provided, very few are up to standard. A more thoroughgoing and effective program presentation, or a brochure that is authentic and verifiable and describes simply the project for which funds are required will greatly benefit all concerned.

Paper agencies for the disabled, and patronizing professionals and volunteers have all contributed to the suspicions and conflicts that have developed. The mushrooming of organizations for and of the disabled has caused immense hardship and strife.

It is hoped that with the adoption of the new bylaws and constitution of Rehabilitation International for equal and full participation of the disabled, there will be greater cooperation between those of us who have a disability and those of us who have not. At least in this instance, let it be said that the '80s will usher in an era of dynamic cooperation between all consumers, at all levels of organization and function, and that we genuinely do not differentiate between the have's and the have nots.

ORGANIZING AN ACTION GROUP

John Simkins, Chairman
Action for Research into Multiple Sclerosis, England

In Britain in the early 1970s, a great deal of research was done which might have led, but in fact did not, to a major discovery of use to people with multiple sclerosis. Very little of what was done could be termed "new" work, and in any case it was confined strictly to the regular medical disciplines. Anything outside these parameters was called "quack" and quickly exiled. Even recently we have known an entire proposal to be rejected with scorn on the grounds that the results would be difficult to measure. This despite much subjective evidence of real benefit to sufferers who were already individually "researching" themselves.

But if the approach to research could be regarded as miserably stereotyped, then the treatment of patients and of publicity was positively juvenile. Very few people were told what their ailment was. There was little or no advice on what they might do about their condition. The others, the vast majority, usually found out when it was too late to make the most of their remaining active life. Generally speaking, doctors' responses to their MS patients were patronizing and singularly unhelpful, probably because they knew there was nothing they could do. Certainly, it was considered "harmful" to discuss the disease with a patient, and irritation was the order of the day if they were pressed for information.

People were encouraged to visit a neurological clinic annually, or possibly every six months if their relapses were more frequent. In between, they were left very much to their own devices. The only authorized treatments were, and still are, merely symptom palliatives, and very short-term palliatives at that. With almost every one of the treatments was the possibility of adverse side effects, often considered by the recipients as worse than the symptoms they were used to suppress. Unfortunately, this situation has not greatly changed, and some of these "treatments" are still used.

Counseling was really quite primitive. There were, until comparatively recently, no counselors trained specifically to deal with MS people. Not surprisingly, many patients dared to have families and dependents. Rarely, if ever, was it thought that the families needed help, and there was no time to consider them anyway.

If there were any concern shown for the needs of the mind, it usually took the form of suggesting such devices of occupational therapy as basket making and similar activities totally unsuited to folks who could not control their movements. As for the spirit, well, the

Lord was good, his beneficence was all around us, and we should be grateful for his goodness. Right and proper as that may be, it did not help the individual who wanted to work, but could not; who wanted a full social life, but was prevented from joining in; and who wanted sexual fulfillment, but was told, if it was ever mentioned at all, just not to think about it.

Not a happy environment in which to have multiple sclerosis, and one which was bound to lead eventually to a revolt against the system. The revolt came in March 1974 with the formation of the Multiple Sclerosis Action Group. Six months later the group was registered as a charity and renamed A.R.M.S. (Action for Research into Multiple Sclerosis).

The Establishment of A.R.M.S. and Its Goals

The beginning of 1974 found MS like a Sleeping Beauty--one hundred years of research older, with the world and all its conditions, inhibitions, and opportunities fast changing around us while we steadfastly maintained the status quo.

But there was a growing unrest amongst MS people who, through a lack of positive information and the clumsy response of authority to their inquiries, had no way of understanding what was being done for them and to them. That question proved to be the spark that finally pushed us over the top into a militancy which upset the comfortable world of the nonaccountable expert.

Prompted by a controversial press article, 30 people, unknown to each other until that time, met and decided to form the group. We had the grand reserve of £32 ($64). OK, so we had very little money, but we were certainly big on ideas.

1) *We were going to change the face of medical research by stimulating new and unorthodox research.*
   It would cost thousands, they said. Well, we had £32 and would just have to raise the rest. (Our budget for 1980 is well over £100,000.)

2) *We would inform and educate MS people into a better understanding of the disease and of how it could be more effectively managed.*
   Using many written words and a unique style of public meeting, we have helped bring about in Britain a dramatic change of attitude toward the disease. People know about it; those who have it discuss it amongst themselves and with

their medical advisors; researchers stand up in public to explain their work and why they are doing it; and just occasionally, lay people are even allowed to participate in project management.

To help inform and educate, we planned to produce a magazine for our members. It now appears bi-monthly, has an avid readership, and enjoys a thriving correspondence.

3) *We would tell the general public about the disease to increase awareness of its cost in both human and economic terms.*

The measure of our success lies in the current high frequency of mention and discussion on TV, radio and in the press, all of which provides a useful background for fund-raising activity.

4) *We would operate a telephone counseling service for MS people to fill the gap left by the limitations of local counseling availability.*

We selected and trained our counselors and have run the service day and night for four years. In that time, we have handled more than 5000 calls and learned a lot about the MS person and the MS family.

This unique knowledge has certainly influenced our policies and activities and resulted in a confident and growing membership now running at well over 1500.

The Organizational Structure of A.R.M.S.

The A.R.M.S. organization is built upon a set of rules, three of which were to be regarded as fundamental.

1) *That control is vested in a committee comprised entirely of MS people and MS related members.*

The founders were adamant that those with the disease should have the power of decision, rather than leaving control to nonsufferers, however well-intentioned.

2) *That A.R.M.S. should not engage in local welfare work.*

The British Multiple Sclerosis Society has a large, loosely structured network of branches, each providing friendly companionship and aid in its own locality. We saw it as a total waste of resources to duplicate that service in any way. Our only practical welfare activity is the telephone counseling service.

3) *That A.R.M.S. should remain an entirely voluntary, self-help organization with no paid officials or staff.*

That is as true today as it was in 1974. Everyone works and gives freely of his/her time, skills, expertise, and money. We receive no government or official grants or funds of any kind.

The 15-member governing committee meets, on average, ten times a year. In addition, there are special meetings for fund raising and for considering grant requests. The committee also visits each sponsored laboratory or trial center at least once a year.

The officers act as executive directors, insuring that essential and routine functions are carried out effectively. They are in constant contact with their fellow committee members. Each member has an allotted task for which he or she accepts responsibility, so that the work is shared as far as possible.

There is an annual general meeting where the results of our year's efforts are presented and the plans for the next year are considered. Those are always lively meetings due to the strong interest of the members and their personal commitment to the job of keeping up the pressure and urgency in the search for an answer to MS.

We have no head office or, indeed, offices of any kind. The secretarial and administrative work (no less voluminous than that of other charities) is all done in members' private homes. Our administration secretary has a team of experienced helpers who, while living many miles apart, act as her office staff doing jobs suited to their individual capabilities.

They and the committee are in constant contact by telephone, and we have found that there is very little that cannot be done by this method. Certainly, we manage to deal effectively with a large and varied postbag.

There is no doubt about the financial advantages of this system which leaves us free of rent, rates, and other running expenses inherent in the fixed, head office type of structure.

A.R.M.S. work is leisure time work, because most committee members hold full-time jobs in industry, commerce, or the professions. This means that meetings are held in the evenings, and nearly all the practical activities are done after work and at weekends.

Personal visits are essential if A.R.M.S. is to continue to thrive. Several of us spend a great deal of time travelling around the UK "selling" the group and its work, and engaging in development functions at research centers or in educational activities with interested people who want to know "what is being done."

A.R.M.S. Research Involvement

In trying to satisfy our special commitment to the stimulation of research, we have found ourselves sponsoring work which, for reasons of economy or political expediency, was in danger of closing down. This is in addition to helping other viable projects that have a special need for support to speed up the work or enable additional aspects to be studied concurrently.

We are actively involved in the management of two projects and, interestingly, have found an enthusiasm on the part of those researchers for the contact with MS people which we provide. When, in 1974, we declared our aim of getting closely involved with scientists and doctors, the idea was ridiculed by the medical and charity establishments.

We were insultingly told that technicians would refuse to talk or work with us because: 1) we as laymen would not understand the technicalities of research, and 2) the scientists would be incapable of explaining their work in terms we could understand. Both surmises were wrong. We can and they do communicate admirably.

Conclusion

We have learned much in the last six years about working together with nothing to bind us but a common purpose. There are no sanctions to impose, and people are free to come and go as their physical capabilities and consciences dictate. Despite their handicaps and often distressing symptoms, members consistently respond to a leadership that insists on a program of creative progress and on the inestimable value to the patient of constructive self-help.

We have all learned a lot about ourselves and the meaning of voluntary commitment. On the way we have each made many friends. In fact, our speciality is the Friends of A.R.M.S. group, several of which are firmly established around the country. These groups are solely concerned with raising money, and they are remarkably good at it.

There can never be a magic formula for success in running a voluntary organization. However, for us, certain key factors are clearly indicated as essential:

1. A firm, skilled, and sensitive leadership.

2. A confident but questioning membership suffering from limitless enthusiasm.

3. A busy program regularly throwing up fresh "high spots" of excitement and interest.

4. Well-presented information designed to stretch the majority just enough to provide challenge.

5. A businesslike approach to raising funds in which the group's commitments are high (a quarter million dollars), but are presented in such a way that individual members are motivated to set their own manageable targets.

After more than a century of traditional research on MS and our own six years of involvement, we are more than ever convinced of the need for our particular brand of "patient power."

TRADE UNION PARTICIPATION

Liam Maguire, Chairman
Irish Wheelchair Association, Ireland

I wish to commence by extending warm fraternal greetings from the Irish Congress of Trade Unions to all brothers and sisters here present, disabled and nondisabled. We extend the hand of friendship to all those who have common cause with us in bettering the lives of all, especially disabled and working people. In presenting this paper, I will of necessity be representing and discussing the Irish trade union viewpoint. To do so, I will first give you some statistics about the demographic structure and vocational groups in my country.

We have a comparatively small population of 3,365,000. However, we are unique in Western Europe in two respects. One, our population growth is rapidly increasing; and, two, we have a very young, educated and healthy people. This raises major problems. Half of our population is under 25 years of age. Thirty-two percent is under 15 years of age. This unique demographic structure means that a small work force has to support a large part of the population. It is, therefore, obviously necessary to maximize the quantity and quality of the work force to use all possible sources of manpower to the maximum of ability. The Irish trade union movement is acutely aware of these needs.

The total work force is 1,043,000 of which 762,000 are employees. The membership of those unions affiliated to the Irish Congress of Trade Unions is 464,000--44% of all employees in the country. These sort of numbers obviously give strength to the trade union central organization and give rise to the possibility of centralized bargaining. This is what has occurred.

Since fiscal 1969-70, all wage negotiations in Ireland have been conducted in a centralized fashion under successive national agreements. These agreements were negotiated in a bipartite manner between the employers' organizations and the unions with the government participating as an employer of the public sector, not as government. The unions attempted to draw the government into tripartite talks in which the agenda would include social and economic planning. These attempts were unsuccessful (with the exception of one such tripartite agreement which proved abortive) as the government refused to enter talks as a partner.

However, the Irish Congress of Trade Unions' persistence, plus a little bit of maneuvering, succeeded in 1979 in getting a tripartite national understanding between the employers, the congress, and the government which included elements of social and economic planning. Some of these elements were the establishment of a National Development Corporation, a comprehensive health service (which covers 90% of the

population), and a commitment by the government to the elimination of unemployment--all long-cherished congress aims. The precedent has now been set for further tripartite agreements, and the extension of trade union influence over social and economic planning.

The 1978 Resolution on the Rights of the Handicapped

In 1978, the General Executive Committee of my trade union, the Federated Workers' Union of Ireland, submitted a resolution to the Annual Delegate Conference of the Irish Congress of Trade Unions on the rights of the handicapped:

Mindful of United Nations General Assembly Resolution 3447, "Declaration on the Rights of Disabled Persons," adopted on 9 December 1975 and being aware of the contents of the paper, "A Fair Deal for the Handicapped," delivered by the Chairman of the Irish Wheelchair Association to the Union of Voluntary Organizations for the Handicapped on 15 October 1977, this Conference instructs the General Executive Committee of Congress to:

1. *Re-title the Sub-Committee on Protective Legislation to include "and Legislation for the Handicapped" and to expand its membership.*

2. *Make immediate and strong representation to the Government to:*

   (a) *Declare a date by which all existing buildings and services occupied by Government Departments, Local Authorities and other State bodies shall be made fully accessible to the physically handicapped.*

   (b) *Ensure that the already overdue National Building Code will have adequate provisions for accessibility for the physically handicapped and punitive penalties for failure to observe same.*

   (c) *Establish in conjunction with Diploma and Degree awarding bodies a method whereby the curriculae and examinations for Architects and Civil Engineers shall include accessibility for the physically handicapped.*

   (d) *Declare the principle that public transportation must be made accessible to the physically handicapped and to give a commitment that future capital expenditure will include provision for such accessibility.*

   (e) *Ensure that all schools, colleges and universities are made fully accessible to the physically handicapped and to give a commitment that future capital expenditure from State*

funds will be given only where there is provision for such accessibility.

(f) Establish that in each Planning Office there is one named individual with specific responsibility and training for ensuring that accessibility requirements are met.

(g) Recognise that a handicapped worker without a job is unemployed rather than ill by transferring the responsibility for training and placement of the handicapped to the Minister for Labour.

(h) Publish the entire Resolution and Declaration on the Rights of Disabled Persons in the national newspapers in order to comply with article 13 of the Resolution.

3. *Enter into discussions with the Government and the Employer-Labour Conference with a view to establishing a regular comprehensive medical check-up for every worker in the country to prevent, or to detect at an early stage, any serious illness or defect.*

4. *Make representations to the Taoiseach (Prime Minister) to appoint a Minister of State for the Handicapped with specific responsibilities to include liaison with the Irish Congress of Trade Unions and the national voluntary organisations catering for the handicapped.*

5. *Include a section in next year's report to advise Conference of progress on this Resolution.*

Following supportive debate, the resolution was unanimously adopted on Friday, July 7, 1978 and is from thenceforth part and parcel of congress policy until the decision of the delegate conference is reversed by a future delegate conference--an unlikely event. The rights of the handicapped is now an item for consideration at the next round of talks on social and economic planning.

A Study on the Needs of the Handicapped in Ireland

In 1973, the National Economic and Social Council was established by the government. Its main task is to provide a forum for discussion of the principles relating to the efficient development of the national economy and the achievement of social justice, and to advise the government on the application of these principles. The membership of the council comprises a chairman, 10 persons nominated by agricultural organizations, 10 persons nominated by the Confederation of Irish Industry and the Irish Employers Confederation, 10 persons nominated by the Irish Congress of Trade Unions, 10 other persons appointed by the government, and 6 persons each representing a relevant government department.

The National Economic and Social Council established a number of subcommittees to study and report on specific areas of social and economic planning. One of these committees is the Social Policy Committee, in which the Irish Congress of Trade Unions takes a particular interest. The council published a report in 1975, "An Approach to Social Policy," and I quote from it:

> *...any change is desirable which brings nearer a situation in which the disadvantaged in the community are assured of equal access to education, medical care, satisfactory housing, and satisfactory jobs, in which opportunities for improving their living standards are as nearly as possible equalized...*

After deliberation and discussion of this report it was agreed that, based on the philosophy of the rights of the handicapped, the goal of rehabilitation policies is ultimately full integration. Often this means the need to positively discriminate in favor of the disabled person. As the Snowdon report illustrates, integration for the disabled means a thousand things.

It means the absence of segregation. It means social acceptance. It means being able to be treated like everybody else. It means the right to work; to go to cinemas; to enjoy sports; to have a family life and a social life, and a love of life. It means being able to contribute materially to the community; to have the usual choices of association, movement and activity; to go on a holiday to the usual places; to travel without fuss on public transport; to be educated to one's maximum potential with one's unhandicapped peers where possible.

Many of these are merely aspirations within the Irish situation. The goal of planning must be to make them a reality. The council therefore, in September 1978, commissioned a further study which attempts to provide an overview of the situation relating to the handicapped person in Ireland. The impetus behind this decision came from the Irish Congress of Trade Unions' representatives on the Social Policy Committee.

The focus of the study is essentially on needs rather than disability groupings. Within this framework the following areas are examined: identification, education, employment, community services, income maintenance, residential care, mobility, and preventive aspects. I am writing this paper early in 1980. I expect that the study entitled "Major Issues in Planning Services for Mentally and Physically Handicapped Persons" will have been published in the spring.

This study has the status of a government-sponsored report and carries enormous credibility and importance. In effect, the government asked for this report. When it gets it, it cannot ignore it.

Fostering Legislation

Following the adoption of the resolution on the rights of the handicapped in 1978, the Protective Legislation and Legislation for the Handicapped committees of the congress scheduled a two-day seminar on the rights of the disabled on May 19-20, 1979. This seminar was attended by representatives of the largest and most influential unions within the congress. At this seminar it was announced that the Executive Committee of the Irish Congress of Trade Unions had served a demand on the government to produce a green paper on the rights of the disabled so that interested parties could examine such a paper and propose amendments or addenda, this to be followed in due statutory process by a white paper and, finally, by an act of Parliament.

You can see that I have outlined for you the genesis of the Irish trade union movement's position on the rights of the disabled:

1. 1975: The National Economic and Social Council publishes, through the Social Policy Committee, "An Approach to Social Policy."

2. 1978: An Irish Congress of Trade Unions' initiative within the National Economic and Social Council results in the commissioning of a scientific analysis of major issues in planning services for the handicapped.

3. 1978: The Annual Delegate Conference of the Irish Congress of Trade Unions adopts the resolution, "Rights of the Handicappped."

4. 1979: The Irish Congress of Trade Unions serves a claim on the government to produce legislation.

The fifth step will happen in late summer or early fall. When the tripartite discussions commence on a new round of centralized bargaining with the employers and with the government, the Irish Congress of Trade Unions will be demanding a response to its May 1979 claim for legislation on the rights of the handicapped. The study identifying the need areas will have been accepted by the National Economic and Social Council and submitted to the government for consideration of the "major issues" involved. The scenario is complete; the next move is up to the government.

The Need for Statutory Support

As I stated at the beginning, I am representing and discussing the Irish trade union viewpoint. That trade union movement subscribes to the philosophy of egalitarianism. It is, therefore, incumbent on that movement to consider the special requirements of the handicapped

individual to enable him or her to play an equal role in society, so far as is possible. The rights of the handicapped can best be advanced through the statutory underwriting of the position of the handicapped individual in society, so as to ensure the maximization of that individual's ability to perform a social role.

Maximization of the handicapped individual's ability must not be subject to cost/benefit analysis as the criterion in deciding whether or not to provide aids or services to the handicapped. We, the body politic, must decide that the maximization of the handicapped individual's ability is the right of that individual, and the state is obligated to provide such aids and services as are required. To do otherwise is to accept a degree of lesser ability as being the apogee of the aspirations of any handicapped individual.

Without a legislative foundation, it is comparatively easy to reduce the level of aids and services during times of social or economic stress, and to justify this reduction by accepting a lesser degree of ability. Of course, the inevitable outcome of such a policy, when carried through to its extreme, is best exemplified by the bizarre solution to the "problem" of the handicapped which was adopted less than four decades ago by the architects of the Third Reich.

HANDICAP COUNCILS: A SWEDISH EXPERIMENT

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On the following pages we will present the regional and local Swedish handicap councils. The councils are intended to be advisory and coordinating bodies where representatives of the disabled discuss current problems with representatives of the various local and state authorities. There are now handicap councils in all of Sweden's 24 counties and in more than 250 of Sweden's 278 municipalities.

In order to get a clearer understanding of how these councils function in practice, the National Council for the Handicapped initiated a study which was published in 1978. The results of this study are summarized in the present paper. We will also try to reflect some of the discussions which have gone on since the report was published, and the conclusions which can now be drawn as to the future of these councils.

In order for the study to be as concrete as possible, we chose to study the activities during one single year (1976). Twenty-four municipal councils and seven county councils were chosen at random and were thereafter carefully studied. We started by studying the minutes in order to get an idea of what matters had been treated at the meetings. The secretaries of the councils gave supplementary information during detailed interviews. Thereafter we interviewed 343 out of 364 members in all of the 31 councils. The method used was telephone interviews. The interviewees received a questionnaire by mail and answered the questions over the phone. This method proved profitable, both as to frequency of answers (90%) and the contents.

In order to get an idea of how the activities of the councils were judged from "the outside," a number of responsible civil servants in important committees (government and municipal) were questioned by letter. We also tried to measure opinion within the organizations by sending letters to the chairmen of the regional branches of the organizations of the disabled. These inquiries reached a total of 161 persons.

The third step of the investigation was the holding of six regional conferences with a total of 185 participants. Most of these participants were active in handicap councils, both in those councils covered by the study and those which were not. At the conferences, the preliminary results of the study were presented, and the participants were given the opportunity to make their comments. The conference acted as a control, showing whether the study was really representative. At these conferences, half of the time was devoted to discussion about the future of the handicap councils, in light of the findings reported in the study.

The Handicap Councils within the Swedish Administration System

As seen from abroad, Sweden is a centralized homogeneous state. Uniformity is great all through the country. There are no less than 1,600 kilometers from the plains in the south, resembling the fertile farming areas of Middle Europe, to the mines and forests in Lappland far north. In spite of the great distances and the great regional differences, there is everywhere the same administrative system with its center in Stockholm. Medical care, social welfare, schools, etc. are organized in the same manner, and the clearly expressed intention is to even out regional differences.

This uniformity is, however, only partly due to strict centralization. On the contrary, during the 1970s, central control diminished. The most typical example of this is the fact that the municipalities and the counties now administer two-thirds of all expenditures in the public sector. The share administered by the state authorities has constantly shrunk. The greatest percentage growth of expenditures is found in the counties whose councils have as their principal task the administration of medical care.

Municipal and County Administration

The key role played by local government in Swedish society was made possible by two local government reforms. These reforms led to a decrease in the number of municipalities (kommun) from about 2,500 in 1951 to no more than 278 at present. The last merger took place in 1977. It is this new system that is reflected in our study. At present, in most municipalities you will find specialized local committees (nämnd) in charge of various sectors. They have a growing staff of employees. This means that problems of coordination between different municipal committees have become more frequent. Handicap issues, which fall within all sectors of municipal activity, present one such coordination problem. The handicap councils are intended to act as bodies for better coordination in this area.

We should also mention that the number of politically elected representatives has diminished considerably because of the merger of municipalities. In 1951 there were 200,000 representatives. After 1977 the number is only about 55,000. This is part of the so-called municipal democracy problem. The handicap councils have been discussed from this aspect also, that is, the wish to get more people involved actively in local self-government.

At the regional level there are the 24 counties (län), each with its county council (landsting). For more than 100 years, the principal task of the county governments has been to provide medical care for the

inhabitants of their area. In each county there is also a national county administration, which is responsible for regional planning. This county administration is headed by a board. The board members are appointed on the basis of election results in the county. In addition to the county administration board, there are several minor regional state authorities responsible for construction, employment, and schools. Thus, the county handicap councils have different kinds of coordination problems than the municipal councils.

National Administration

At a central level there are of course the parliament (riksdag) and the government (regering), and in addition about 70 different central administrative agencies (ämbetsverk).

The ministries (departement) of the Swedish government bear little resemblance to those of other countries; the actual administration rests upon formally independent agencies. Therefore, the ministries are very small units and are not suitable for detailed central control. For example, the Ministry of Local Government is responsible for the 24 counties and 278 municipalities. The number of employees in this ministry is about 50, including secretarial staff. This can be compared with the largest county administration that has about 1,500 employees. The Ministry of Health and Social Affairs, with a budget of over 30 billion kronor had, a few years ago, only 91 employees.

The central administrative agencies, on the other hand, are quite large. Due to a unique Swedish tradition, they are independently responsible for the application of laws and regulations within their area. Cabinet members and their employees cannot, and are not allowed to, interfere with the handling of matters within the offices. A member of the Cabinet is not the principal of "his" offices, and neither is he responsible to the riksdag for decisions made by the offices.

The uniformity of Swedish administration is largely due to the activities of the central administrative agencies. However, during the 1970s, the decentralization policy affected their governing and controlling roles. According to present doctrine, the government offices are to act as "advisors" and "policy-makers"--something in between an advisory bureau and a research institute.

The National Council for the Handicapped

It is within the framework of this system that we find the National Council for the Handicapped (Statens Handikapprād - SHR). The SHR has 18 members appointed by the government; in reality, these mem-

bers are chosen by the government offices and organizations represented on the council. The chairman is a member of Parliament. The following are represented on the board:

- The National Labor Market Board, National Board of Industrial Safety, National Housing Board, National Board of Town and County Planning, National Social Insurance Board and National Board of Education

- The Swedish Association of Local Authorities and the Federation of County Councils

- The organizations of the disabled.

The task of SHR is to promote better living conditions for the disabled, and its principal duties are:

- to follow measures taken by society for the benefit of the disabled, and to further the coordination of such measures

- to encourage the authorities of the community to pay attention to disability issues in their work

- to initiate improvements in the disability area

- to follow and further research in the disability area

- to support the activities of handicap councils in municipalities and counties

- to provide information services.

The SHR is a body for cooperation and coordination, just as the regional and local councils are. The national council has a rather small secretariat in Stockholm that has close contacts with the county and municipal handicap councils (länshandikapprad-LHR, kommunhandikapprådKHR). However, it must be observed that the National Council for the Handicapped has no power to direct the activities of the county and municipal councils. In this, as in other areas, there is opposition to any kind of central control.

Voluntary Organizations

In this uniform but decentralized system, voluntary organizations play an important part. They have a number of different channels through which they can influence matters.

A unique position in Swedish society is that of the so-called popular movements (folkröralser). According to a prevalent definition, a popular movement is "an organization with a great number of members all over the country that has a democratic construction and has a non-materialistic (idealistic) element in its activities." Of course, this definition applies to most of the 24 Swedish organizations of the disabled, even if some of them, particularly those uniting groups of medically handicapped persons, are small and have few local organizations.

The Swedish organizations of the disabled are different from such organizations in most other countries in that they are predominantly managed by disabled persons themselves. Often the majority of the members are themselves disabled, and, on the boards and other decision-making bodies, the disabled members have the decisive influence.

It is estimated that the organizations of the disabled in Sweden have a total of nearly 300,000 members. The five biggest organizations are:

- The Swedish Association for Traffic- and Polio-injured (RTP); 50,000 members
- The National Association of the Handicapped (DHR); 40,000 members
- The National Association against Rheumatism (RMR); 36,000 members
- The Swedish Association of the Hard of Hearing (HFR); 34,000 members
- The Swedish Diabetic Association (SD); 23,000 members

Among the very smallest organizations, we could mention P-Club for stammerers (350 members), the National Association for Thalidomide Children (200) and the Swedish Association of the Deaf-Blind (120).

In addition, organizations with memberships totalling 230,000 are united in HCK, the Central Committee of National Associations of the Handicapped, which defines itself as an organ for cooperation. The aim of HCK is to represent the common interests of disabled groups in a united front. Since 1964, HCK functions at a national level, and nowadays also in each county and many municipalities.

In Sweden, as in other countries, there is a tension between the double role of handicap organizations. On one hand, they want to be combat and service facilities. On the other, they need public financing, and they are expected to cooperate in decision making and administration.

At the national level these "pressure groups" cooperate regularly in the commissions of inquiry which are normally formed in preparation for all reforms and other important political decisions. Before the government decides upon the proposals of such a commission, they are always sent out to gather the comments of a great number of authorities and organizations. This means that all those interested in the matter have an opportunity to make their views and comments known.

It is common practice that in their turn, the boards of the national organizations let the regional and local associations have their say before reports are made out and handed over to the government. There are always at least 300 commissions of inquiry at work simultaneously in Sweden. About 100 reports are finally presented each year, and 100 new commissions are appointed. This standard procedure is said to explain the factual and dispassionate spirit which prevails in Swedish politics. On a regional and local level, decisions are also usually preceded by close investigation. Generally however, only other authorities within the county or municipal administration have a chance to give their opinions. That is why it was considered an important accentuation of the status of the handicap councils that, as stated in the statutes of 1971, they were identified as bodies to whom such inquiries were to be referred.

The Structure and Status of the Handicap Councils

The municipal council is the supreme policy-making body elected by the citizens. The business of the municipality is run by an executive committee and other committees. The executive committee is the managing and coordinating body. However, a great deal of the practical work is done independently by the committees, the members being appointed by the councils in proportion to their political representation in the municipality. This means that the committees are made up of laymen with political responsibilities. In principle, all decisions are to be made by persons who are politically responsible, not by civil servants.

The most important committees in this connection are those imposed by law: the central social welfare committee (responsible for social welfare, child care, and temperance care), the building committee (planning and building), and the education committee. Out of the committees that are not obligatory, we want to mention two: the culture committee and the leisure committee (sports and recreational facilities).

The practical work is carried out by employees. Normally, every committee in municipalities with more than 10,000 inhabitants has its own administration with a head who is responsible to the committee. Only in the smallest municipalities do they have one general municipal office with some departments servicing the various committees.

Administrative Position

How were the handicap councils to be integrated into this system? This was a controversial issue at the start. Almost unanimously, the organizations of the handicapped wanted the councils to be directly subordinate to the executive committees of the municipalities in order to have the greatest possible weight and authority. However, the Association of Local Authorities (the powerful interest and service organization of the municipalities) recommended that the councils be attached to the central social welfare committees. This is how the matter was finally settled. Only three of the councils in our study were directly subordinate to the executive committee.

It seems that the representatives of the organizations of the handicapped have now accepted this arrangement. Several parties have said that because the councils are attached to the central social welfare committees, they can intervene at an earlier stage of decision making than would be possible if they were subordinate to the executive committee.

The same argument has been heard concerning the county handicap councils. The position of these councils in the system is difficult to describe in a simple matter. With few exceptions, the county handicap councils belong to some other coordinating body--generally, a body which was formed in the early 1970s by the municipalities and county councils jointly in order to coordinate, for example, medical care and social welfare.

In our study, it has not been possible to confirm any connection between the organizational position of the councils and their degree of activity and efficiency. How active a council is, and how great the results achieved, seems to have a much more down-to-earth reason: the amount of time the secretary (handicap councillor or other civil servant) can devote to the affairs of the council.

The status of the councils could also be measured in another manner: whether the politicians who are members are "heavy" or "light." As politicians of great weight we could classify, coarsely, those who were chairman of one of the big committees or who were members of the executive committees of municipalities or counties. If we allow this definition, we can assert that somewhat more than half of the politicians were "heavy." This must be interpreted as a sign of great interest in the handicap councils on the part of the political parties.

In the municipal handicap councils, almost all of the members representing society are politicians. And almost one-fourth of them were also members of some organizations of the disabled. Only 13% were civil servants.

In the county handicap councils, the share of politicians is lower, 59%. But on the *whole*, it must be said that the organizations of the disabled have had their wish fulfilled, i.e., the presence of responsible politicians, preferably at least one of them "heavy," in the councils.

Representation of the Disabled

The representation of the organizations of the handicapped is a somewhat controversial issue. One reason is that the number of organizations is great, and there is not room for all of them at one time. In order to keep the councils down to a size which enables them to work efficiently, they are usually made up of about 10 - 12 people.

The authorities wished to get both a comprehensive and a concise picture of the demands of the disabled. The solution found was a division into five handicap groups: the motor disabled, the visually impaired, the hearing impaired, the medically disabled, and the mentally disabled. Each group ought to have at least one representative in each council. In spite of this, it was feared that all associations would not be able to make their voices heard.

Our study shows that the handicap groups are very evenly represented, but that these groups are dominated by the four organizations that are most firmly established. For example, these four organizations had 75% of all seats in the councils. The four were DHR (motor disabled), SRF (visually impaired), FUB (mentally disabled), and HFR (hard of hearing). Ten organizations were entirely unrepresented in the 31 councils studied.

The uneven representation does not, in itself, have to be a disadvantage, if the council member represents his or her own disability group and not only the organization. However, this is not always the case, according to our study. In the test interviews, we found a statement to the effect that the disability representatives in the council "only bring up the wishes of their own organization." We asked the representatives of the authorities to comment upon this, and more than half considered that this tallied with their own experiences. According to the secretaries only more than one-third of the disability representatives had, during 1976, brought up a matter which chiefly concerned another organization than their own. One way of solving these problems is to form reference groups where all organizations are represented. In one-third of the councils studied, the organizations had formed such reference groups (but the additional work frightens some of them).

Finally it ought to be mentioned that it is always the handicap movement that chooses the representatives, through cooperating bodies or otherwise. Not in any case did the municipal authorities or other officials elect the representatives of the disabled.

Activities of the Councils

Intended Scope of Activities

The governmental commission which initiated the handicap councils described them as coordinating bodies, where experts were to meet and confer on the efforts to be made by society for the benefit of the disabled. However, the Association of Local Authorities and the Federation of County Councils dampened these ambitions. In their recommendations, they said that the councils were to be bodies for mutual consultation. They were also careful to point out that the councils could not be vested with any decision-making rights. After a few years, the Association of Local Authorities was forced to issue a circular reminding parties not to forget this limitation.

In spite of all this, there were important issues handed over to the councils. They were to comment upon official inquiries and were thus to be part of the regular municipal decision-making process. They were to point out desiderata, follow changes in services offered by society, and give their motives for increasing financial resources. This last is naturally rather unusual in municipal affairs, but it expresses the ambition at that time to improve services for the handicapped. In the policy for the county handicap councils, some more tasks were added: to suggest priorities with regard to certain measures to be taken, to take the initiative in integrating disabled persons in all training and education programs, to suggest how the money provided by the county council be divided among the organizations, and to take part in the planning of handicap care.

Actual Activities

It is against this background that we will now look at what the handicap councils did during one year.

First of all, it must be said that the councils have never gone further than the limits set. They have not received nor procured for themselves any decision-making right. Only in a few councils was the secretary of the opinion that, in practice, the council had the right to make decisions independently, and in two cases it was simply to divide granted money between organizations.

This does not prevent representatives of the organizations from strongly feeling that they ought to have their own right of decision. Practically half of them considered that the councils ought to be able to decide for themselves on measures to be taken in the disability field, particularly as to changes in the physical environment. However, this would mean a deviation from the present doctrine that each committee and authority is responsible for disability issues within its own sector. That politicians would be willing to give the right of decision to a body which had no political responsibility would be another change in policy. Among the representatives of society in the council, there are only vague sympathies for giving the councils a right to make decisions.

How about the other tasks entrusted to the councils?

As we have said before, it is important in the Swedish decision-making process to be established as a part of the commission of inquiry system, i.e., that you are regularly given the opportunity to comment upon current proposals and plans. Our study of the handicap councils gives a rather ambiguous picture of their success in this respect.

Of the 31 councils studied, we found that 11 had never commented on any of the inquiries, 12 had done so once or twice, and 8 had commented upon 3 - 12 inquiries. The most common inquiries were about town planning and building plans. In the Swedish Parliament, two proposals have been made in vain asking that the municipal handicap councils be obligatory references in matters of this kind.

The annual drawing up of budgets is no doubt the most important occasion to "point out desiderata and give motives for increased financial resources." Our study shows that only two municipal councils and four county councils were involved in budget business during 1976. And in these cases the involvement concerned lesser issues, such as dividing grants among the organizations of the disabled.

Nine out of the 31 councils have, during the year studied, contributed to joint activities of the authorities. One example is a council that took the initiative for a joint conference concerning grants for the adaptation of dwellings for disabled persons. Six of the councils contributed to some kind of joint activity by the authorities and organizations of the disabled. To some extent, the councils reached the aim of contributing to increased cooperation within the field. The provision of information, both external and to staff, was rather more ordinary. More than half of our councils had been involved in information activities.

We have also studied the minutes of the councils in order to see the types of subjects treated. First, let us mention that most of the items in the minutes related to discussions within the group, i.e., exchange of information, etc. Only a scant 40% of the business involved some kind of external action directed by the council to the outside world.

In the municipal handicap councils we found that adaptation of the physical environment is the major subject taken up (39%). The reasons for this, as suggested in our conferences, are partly that these matters are easiest to identify and to take measures to correct, and partly that in these areas there are strong organizations with sufficient representation in the councils. The next largest subject area taken up was the function of the councils themselves (9%). Under the 2% limit, we found many headings, such as work, home service, child care, seeking out disabled persons who need assistance, etc.

In the county handicap councils the distribution is much more even, with medical care being the most prominent subject. This is natural as the county councils are in charge of medical care. But the distribution of subjects also shows that those issues that directly involve the regional authorities of the government (work, social security, education, housing) are less than 12% of the subjects dealt with. It is the business of the county councils which dominates, not questions of cooperation. This is partly due to the fact that government authorities have their own direct contacts with the organizations.

The handicap councils normally meet 3 - 5 times a year. Almost half of them made one or more investigations themselves during the year. This is not a bad figure, if one realizes that none of the councils has a full-time secretary and that half of the secretaries say that they only devote themselves to the councils in connection with the meetings. Twenty-one out of 31 secretaries consider that the time they can devote to the council is insufficient.

Evaluation of the Councils' Activities

The data reported here shows that the activities of many councils do not, by far, correspond to the official guidelines. One possible interpretation of this data is that individuals within the handicap movement and government officials both had unrealistically high expectations at the beginning. In our discussions, most people lean towards this explanation.

But the activities, such as they became, were still highly rated by those who take part in the work of the councils. For example, of

the members, 83% considered that the suggestions of their own councils had "considerably" or "in part" been followed by decision makers. A still greater number considered that the conditions of disabled persons had been improved "to a certain extent" or "considerably" through the activities of their own council. In none of these cases was there any difference between the various categories of members nor between the more and the less successful councils. Most of the members mentioned that the attitudes of the authorities had changed because of the councils, but many also mentioned concrete improvements: "accessible bus terminal," "bevelled curbstones," "magnetic loops in public places," "swimming establishment accessible."

The above statements were made by those directly involved. Although still a predominantly positive evaluation, we found a less positive attitude when questioning the 60 responsible civil servants who did not themselves belong to the council. A majority agreed that the council had contributed to improvements "to a certain extent" or "greatly," but 37% considered that no improvements, or only small ones, had been accomplished.

An evaluation which is just as interesting is that of the chairmen of the regional branches of the organizations of the disabled (101 persons). Here also a majority is positive to the councils, but 47% consider that no improvements, or only small ones, have been accomplished. However, it must be noted that the question asked referred to the conditions of their own members. We can note that the negative opinions were mainly from those associations that had no representatives of their own in the councils and from those representing the heterogeneous group of medically disabled persons. This relatively large number of organizations is, as we have seen, less represented in the councils than those of other groups.

There is reason to turn for a moment to the minority of council members whose evaluation was negative. Some spontaneous comments can shed light on their experiences: "the council takes up too few matters and too seldom," "too slow, sluggish, and too bureaucratic," "because the councils are not decision-making bodies but only informative, I don't believe that they can have contributed to any changes."

From other interviews it can also be gathered that the representatives of the handicap organizations were not particularly impressed by the contribution of the representatives of the authorities. Of the disabled representatives, 40% considered that their counterpart had shown "rather little interest" or "no interest at all" in the work of the councils. A usual comment was: "if the members representing the authorities came to the meetings at all..." Only 6% of those representing the authorities had a correspondingly negative opinion regarding those members who represented the handicap organizations.

The ability and willingness to give information was rated in a similar manner. Only one-fourth of the members representing the disabled were of the opinion that those representing the authorities gave "good" information regarding the current affairs of their own committee or authority. In contrast, 63% of the members representing the authorities considered that those representing the disabled gave "good" information regarding the wishes and needs of the disabled.

We can discern a difference in roles here. Many of those who represent society consider that it is natural for them to mostly listen, and that the representatives of the handicap organizations must be active and present their demands. It may be both necessary and, sometimes, tactically advantageous not to reveal their own standpoint until the actual decision is to be made in another forum than the council. In one of our test interviews we heard that "the members representing society say yes in the councils and no in their own committees." We tested the truth of this opinion on all the council members, and 20% of them considered this to be their own experience.

Factors Affecting Productivity

Some councils are more active than others. Some councils show more concrete effects from their work than others. We have gathered some different indications of activity and efficiency in order to see whether they coincide with different objective conditions. The only correlation that can be found is with the amount of time the secretary can devote to council work. But the reason might just as well be that energetic and active councils are also able to get sufficient secretarial resources. In view of all the discussions during the 1970s it is worth mentioning that we did not find any correlation between activity/efficiency and the organizational position of the council. The political majority in the municipality or county did not affect the result, nor did having mostly "heavy" politicians in the council. It would be natural to believe that the "older" councils were more "established." However, age seems to have nothing to do with a council's efficiency and activity nor does having a larger number of politicians than civil servants.

In three-fourths of the councils, members are remunerated for attending meetings. This has often been said to be necessary in order to encourage disabled persons to join. But here as well, we must say we did not find any correlation at all.

Evidently one must look for explanations that have nothing to do with organizational or political conditions. Such explanations are

always difficult to measure, such as the members' commitment, ability, and initiative, both in the councils and in the organizations they represent.

There was a small but marked difference in the extent to which the councils were free to act, depending on the political majority. The councils had greater freedom to act in the municipalities and counties that had a nonsocialist majority. That the social democrats have been found to be more restrictive in the councils might be explained by the fact that this party considers that demands by the "interest-organizations" ought principally to be channelled through political parties.

When the councils were first introduced, any people were afraid that, in consequence, the contacts of the organizations with the authorities would lessen, but it seems quite clear that the introduction of the councils has not led to any diminishing of contacts. We found that our interviewees, regrettably, did not have a clear view of whether the introduction of the councils had diminished or increased direct contact between the organizations of the disabled.

The Future of the Councils

The handicap councils will not be written off as an unsuccessful experiment. On the contrary, since 1971 the council form itself has become more and more prevalent in Sweden. The handicap councils were the pioneers. Later on there came councils for adult education for the retired, councils for immigrants, and councils for youth clubs. The Swedish Parliament gave its official blessing in 1976 when it voted for a proposal by the government regarding the development of municipal democracy. In this proposal, there was a recommendation addressed to the municipalities to strengthen contacts with popular movements and to provide for permanent or temporary bodies for cooperation. The motives given were that in this manner "closer contacts are created with groups that are now usually too little represented in the municipal committees." Thus, the councils were to be an extra channel for groups with small political resources. Among these, special mention was made of immigrants, disabled persons, and socially isolated persons.

Models for the Future

At the six conferences that were part of our investigation, time was also devoted to discussions about the future of the councils. During these discussions, three future models quickly crystallized.

The first model asserts simply that the councils should try to live up to the original intentions. The majority of the participants in the conferences backed up this idea--representatives of the authorities, the disabled, and secretaries of the councils. According to this model, future councils would deal with comments upon commission reports, proposals, investigations and surveys, information conferences, plans for coordination, etc. This also means that the secretariats must be given better resources, that there must be a working committee that can handle and prepare matters between meetings, and that there must be a broader representation than at present on the part of the authorities. The participation on the part of the handicap movement must also be formalized, so that the councils can establish their work more firmly in the movement, for example through reference groups that together prepare the meetings of the councils.

The second model suggests that the councils generally remain what they are at the present time, i.e., bodies for mutual information and discussion. In that case, no great resources are needed, but the representatives of the authorities must take a more active part in the work than they do at present, and the representation of the handicap movement must be broadened as much as possible. This model is backed up by several social democrats and also by certain persons in the handicap movement.

The third model calls for the councils to be changed into handicap committees with right of decision on a number of questions, and with the financial resources necessary to carry out their decisions. This long-range program was backed up by a few persons in the handicap movement. It might be added that already, in some Swedish municipalities, special immigrant committees have been formed with immigrant councils acting as reference bodies. This means that prototypes for this third model already exist, and that the resistance based on the principle of not forming committees for a given category of citizens has already been broken.

Conclusion

Our report was published during the spring of 1978, and the large stock was soon exhausted. The National Council for the Handicapped in Stockholm initiated discussions regarding a follow-up. A special working committee, including representatives of the handicap organization, the Swedish Association of Local Authorities, and the Federation of County Councils, plans to sum up the discussions in a special publication. It is also expected that the two associations just mentioned will publish new recommendations. It appears that they

will use the second model as a basis for new policy. This means that they will directly reject the third model and that they will establish that the purpose of the councils is to see to it that disability matters are looked after in all areas.

The recommendation will propose that council activities be deformalized by deleting all present regulations about kinds of activities, composition, routines, remuneration, etc. They will point out new methods, such as regular hearings with representatives of committees and administrations--regular meetings with a common theme, where the nature of the subject will determine what organizations, politicians, civil servants, and others are to be invited. In this manner, they hope to broaden the representation of the handicap movement, and also to reach administrations and committees that at present consider they have neither the time nor sufficient reason to have permanent members serve in the councils. The councils, per the recommendations, are to play a role as initiators, informants, and mediators. Issues are to be taken up by the councils and referred to the authorities for further treatment, and would thus be treated by the bodies where they come in naturally, and in collaboration with the organizations affected. Direct contacts between the authorities and the handicap movement are to be the most important ones.

In this, the municipalities and county councils are partly in opposition to those at the conference who advocated the first model, viz., that the councils should live up to the original recommendations. However, it seems likely that many within the handicap movement will like the accentuation of the independent importance of the organizations. But it is hardly likely that the municipal associations and the handicap organizations will be able to agree entirely.

It must be stressed that the recommendations of the municipal associations are in no way binding. Now, as previously, it depends on the parties in each local and regional council to determine how activities are to be constructed in the future.

III.
Consumer Involvement: Impact on Rehabilitation and Related Services

This chapter focuses on the participation and the results of participation of disabled people in policy decisions that directly affect their lives. Pieter Blommestijn from the Netherlands examines the nature of participation. Donald Galvin from the United States discusses the impact of the activism of disabled people on the independent living movement in the U.S. Richard Hudson-Evans from England describes the involvement of disabled people and their families in the management of attendant care; Per-Olov Kallman from Sweden describes the participation of disabled people in transportation services; Kalle Könkkölä from Finland looks at participation in higher education; and Ken Davis and James Woodward describe participation in information services for disabled people in England. Chapter 4 will look at the societal implications of the participation of disabled people.

PARTICIPATION OF HANDICAPPED PEOPLE IN THE PLANNING, IMPLEMENTATION AND MANAGEMENT OF REHABILITATION SERVICES*

Pieter J. Blommestijn, Head
Directorate of Old Age Policy & Social Rehabilitation, Netherlands

Participation and democratization are sister and brother. Their common father is democracy. Democracy means that a group governs itself; all the citizens together make up a self-governing unit. Since there is general agreement that this is a "law of nature" between people and between the people and their government, there is no argument that participation should be limited to politics and government. It ought to be extended to all situations where power is wielded. Participation is basic to democracy and strongly correlated, therefore, with the possibilities, the structure, the substance, the "image," and the historical evolution of the political democracy in a given country. Without a "full pound" of political democracy, participation is only play-acting.

The Importance of Participation

Participation is nowadays acknowledged to be a basic social right, a fundamental right. The legal ground is broadly determined socially. It is determined in accordance with the principles of the freedom, equality, human dignity, solidarity, fraternity, and mutual alliance of all citizens. Fellow citizens, such as the handicapped, may not be reduced to objects of care and management. They ought to have a say in or at least be informed about the circumstances and conditions under which they must live and work. Especially those who are very dependent on services and institutions should not be jammed into huge anonymous structures.

"Having a say" means co-determination--freely, actively, and with awareness taking part in the process of self-determination. But, as in a political democracy, participation means rights and duties.

Participation is a basic right, as we stated before. It is a micro form of macro-scale democracy. It has social and legal roots. But it means much more than just exercising a civil right. Participation contributes to self-expression or self-realization. Participation is an inborn need of everyone in all circumstances in all countries. Without it, one feels unfree, uncertain, and unsafe; powerless, even threatened, and dependent.

A sociological argument supports participation. If residents in an institution or consumers of social work are asked to contribute in

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*This paper is a condensed version of the original.

some way to the realization of the aims of the institution or the service, it is found that they will identify themselves more with that institution or service. In consequence, the gulf between the board and the clients decreases or fades away.

Participation does not always mean the exercise of direct power; direct power can be delegated to representatives. The delegation however stands under the direct control of the represented and can be withdrawn at any time. This forms the essential difference to political democracy. Participation is, in fact, a correction or a completion of political democracy wherein the citizens want to be involved in their government and administration not only during elections but over the whole legislative period. Participation also brings a counterpoise to professionalism; it can be experienced as organized self-help too.

Participation is not just a technique; it is a social system with social and individual goals aimed at reducing authoritarian, one-sided behavior. It is the defensive weapon of the underdog. By formulating it in this manner, it is understandable that in an authoritarian democratic system, participation is seen as a threat; but even in a good democratic system, participation has to be fought for against establishment and regency.

The Scope of Participation

Participation is possible in state services or institutions, as well as in private, nonprofit services and institutions. It is also possible to participate within foundations, societies, associations, corporations, companies, or public agencies.

Participation, understood as taking part in every aspect of society, should be made possible at all governmental levels (central, regional, and local), in legislative policy making and planning (including participation in advisory bodies), and in the management of services, provisions, and institutions that provide direct care and help to welfare consumers like the handicapped.

Some Provisos

To put it quite plainly, I am not an advocate of services run by or in the hands of clients only. I'm well aware of the attitude that the handicapped are the service providers, that the handicapped are the employers of helpers who are their employees, etc. But, I must state that it is very difficult, not to say impossible, for the handicapped

to distance themselves from all the matters concerned. Nobody can doctor himself in all aspects.

There is a socio-political concern too. The handicapped do indeed provide services, and the customer is king. But, it is the society as a whole that pays for care and cure; society, government and legislator make care possible to the society. I'm aware of examples of self-government by workers, but that applies to the productive sector where other rules exist and where people can bear and must bear their own risks.

Types of Participation

The manifestations of participation are manifold and depend on the given circumstances. We know of no pat, generalizable, uniform format for all situations.

Handicapped persons in long-stay institutions, with care, nursing, and housing day and night, are the most dependent and vulnerable citizens. Their need for participation, in its broader sense, is extremely high. Mostly, they are living in institutions for the handicapped alone. Thus, their situation can be surveyed and may lend itself well to participatory structures.

Some forms of participation in these institutions could be: (a) commissions of handicapped residents, or (b) handicapped patients on the board and in management or, if they cannot participate themselves, (c) participation of their legal representatives (parents, guardians, spouses), or, (d) participation by representatives of associations of handicapped persons, preferably on the basis of election by the handicapped residents themselves.

Participation should be related to the essential aspects of living: nutrition, housing, recreation, the lay-out of the building, the order of the day, the rules of the home (in so far as they produce potential restraints), and the general methods of care and cure. Forms of participation should recognize and be limited by the institution's need for efficiency, the character and objectives of the service, and the financial bearing power of the given society as a whole.

Participation in ambulant services has more difficulties. Most of these services are not for handicapped persons only. Experience shows that clients are more interested in getting information, having a say in their own treatment or therapy, and in establishing a right of appeal with an independent, expert body. They are not as interested in participating on the board or in the management of the service. Alter-

natives here are: commissions or councils of clients (former clients, representatives of associations of handicapped persons, or just the handicapped clients themselves) or structured forms of consultation between management and clients. This latter option may be set up by client associations or by consumer organizations in the field of welfare.

Coordination projects exist in many countries where ambulant services are of a general nature, i.e., where they are intended for the whole population and are not split up into divisions for the handicapped, the aged, the unemployed, foreign workers, etc. The aim of these projects is to coordinate the general services on behalf of client groups that need special attention. These projects are not aimed at "apartheid" but coordinate in order to guarantee that welfare services are not fragmented or split up into categorial and, therefore, isolating "closed shops." We are in favor of this solution, where it is possible. Participation can then be realized by way of membership of the associations of the handicapped on the board or in the management of the coordinating bodies.

Other opportunities for participation are available in the fields of public planning, physical planning, and policy making, including the work of advisory bodies.

Participation as a basic right is not confined to concrete services or provisions. The whole planning machinery is even more important for citizens who are dependent on the products of planning, such as acts, regulations, financial schemes, working methods, service establishments, etc.

Physical planning is a very important sector. Here, decisions are made about where institutions will be located, and about other housing units and their operation. Since housing and living in one's own dwelling are essential possibilities for self-realization, for creating normal social relations, opportunities for participation ought to be created here too.

Requirements for Effective Participation

Participation requires a step-by-step strategy for several reasons. Participation must be learned by inexperienced consumers, circumstances are very different everywhere, and members of boards and people in management are not willing to cede their territory or to share it with strangers. Society, government, administrators, the authorities, etc. are not favorably inclined toward radical change, and participation is one such radical change. Changing the attitude of workers in social welfare agencies and policy makers in government is a laborious process. It takes a long time, hard work, and endurance to persuade unwilling and

uninformed people and to get their support or at least their tolerance.

Participation requires a high degree of organization. It is not a playground for soloists. Participation requires an organizational background, in this case a good organization of handicapped persons. Depending on the situation, the most appropriate organization may be one of handicapped people only or a broader consumers association, trade unions, etc.

Training and education are another important requirement of participation. Especially handicapped persons, focused as they are on treatment, care, and cure in situations of dependence, should know that active participation requires special training and education.

In this respect, we must emphasize the catalyzing or generating function of participation possibilities. Experience shows that it is difficult for associations of handicapped people to get good members on their boards. Participation can thus form an instrument for recruiting more experienced fellow handicapped persons, because participation is a new challenge and requires organizational and managerial capabilities.

Conclusion

As was stated before, participation is a basic right, but it too involves duties and sacrifices. There are no real barriers that prevent handicapped people from participation and co-determination. The organizations of handicapped people have to struggle in order to win the fight for their basic rights. It is very important, therefore, that the associations of handicapped citizens have within their own organizations good examples of participation for all their members, irrespective of age, handicap, social status, education, and intellectual capability. Concentration of power in government and nonprofit organizations is mostly a concentration of power by nonhandicapped people. In order to break these forms of power, handicapped people need unity, solidarity, and mutual alliance. They too need good, realistic information about what participation really is, why participation can contribute to greater well-being and self-confidence and what the limitations of participation are.

POLICY ISSUES IN INDEPENDENT LIVING REHABILITATION*

Dr. Donald Galvin, Director
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In 1978 the Congress of the United States amended the Rehabilitation Act in a remarkable, if not revolutionary fashion. The objective of the U.S. federal-state rehabilitation program was extended to include "independent living" as well as vocational rehabilitation. For the first time, a disabled person's entitlement to rehabilitation services was not predicated upon his/her feasibility for gainful employment and contribution to the GNP.

The Historical Context

I would like to put our independent living movement into perspective by relating it to other social movements that interface with and support independent living. I should mention that I am indebted to Gerben DeJong of the Tufts Medical Rehabilitation Research and Training Center for this analysis.

The Civil Rights Movement. Many of our early independent living advocates were active participants in the civil rights movement in the 1960s. That movement made many disadvantaged groups aware of their rights and had an impact far beyond the movement for racial equality. Civil rights were soon extended to benefit rights, that is insistence upon one's entitlement to income and medical assistance, educational benefits, the right to treatment, and so forth. These benefit rights are often prerequisites for living in the community. For example, many disabled persons will be involuntarily confined to long-term care facilities if they do not have access to income assistance, barrier free housing, and attendant care benefits.

The Consumer Movement. This movement is personified by Ralph Nader, and has resulted in the emergence of public interest law and the enactment of several consumer protection laws. Basic to consumerism is a distrust of sellers or service providers. In theory, the hallmark of the free market economy is consumer sovereignty; however, many feel the professional provider in rehabilitation has been sovereign. With the rise of consumer sovereignty, professional dominance in disability policy and rehabilitation is being challenged.

The Self-Help Movement. The self-help movement embraces a large variety of groups. Self-help groups have emerged for almost every conceivable human condition or problem: alcoholism, drug abuse, death and mourning, homosexuality, child abuse, old age, neighborhood crime, cig-

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*This paper is a condensed version of the original.

arette smoking, child birth, and--of prime interest here--disability Self-help organizations view themselves as mutual aid groups that serve as supports, adjuncts or as valid alternatives to established human service agencies. Self-help organizations are intended to give people the opportunity to exercise control over their own lives and the services they use. They are information giving, consciousness-raising organizations that also help to confer sovereignty on the consumer.

The Demedicalization/Self-Care Movement. Over the last few decades, an increasing number of behaviors once considered sinful or criminal have come to be considered illnesses. They have become "medicalized."

Implicit in the argument for demedicalization is the assumption that individuals can and should take greater responsibility for their own health and medical care. At issue for independent living is the extent to which the management of disability should remain under the dominance of the medical care system once medical stability has been obtained. Disabled persons are insisting that the management of their disabilities is primarily a personal matter and only secondarily a medical matter. A constant medical presence in the lives of disabled persons is said to induce dependency and conflict with the true goal of rehabilitation.

I think you'll find that several of the themes embodied in these four movements play themselves out within the following independent living policy issues and concerns.

Policy Issues and Concerns

One policy concern is to grasp what is meant by "independent living." Unfortunately, federal law, as is often the case, only implies a definition. Let me illustrate this policy issue by contrasting the views of two prominent representatives of different views.

In a journal article on the subject, former U.S. Commissioner of Rehabilitation, Robert Humphreys, described independent living in terms of services that might not have an immediate employment objective, and he spoke of services over and above those traditionally provided. His view represents a provider's view, a fairly typical service orientation.

On the other hand, Lex Frieden of the Texas Institute for Rehabilitation Research and a national consumer leader, speaks about "independent living" from a more philosophical and political perspective in terms of exercising control over one's life based upon having options that minimize dependence upon agencies, institutions, one's family, and,

to some degree, the very services that the professionals are eager to provide.

Thus there are different ideas, views, and values being expressed. However, it is possible to envision a successful scenario which combines these views, i.e., the provision of appropriate and needed rehabilitation services that in time enable a person with a severe disability to achieve greater control over his/her life.

That "happy ending" notwithstanding, it is still fair to say that the consumer view of independent living is the broader view, for independent living is not seen as a competing or subsidiary goal to employment. Gainful employment may be viewed as a very authentic way, but not the only way, to achieve independence.

Federal officials and rehabilitation professionals in our country sometimes use the term "independent living rehabilitation." I have heard several consumers challenge this term both on the basis that it tends to be a narrow view of independent living, and because it tends to assume "independent living" within "rehabilitation." Patient consumers have observed that rehabilitation should be thought of as only one element or stage of independent living. Less patient consumers have asked the rhetorical question, "When are we ever free of rehabilitation; when are we independent of professionals and their agencies?"

Obviously, the stage is set for another policy issue or concern, namely, consumer control and consumer participation in policy development, program management and evaluation. While the 1973 law required that states "take into account the views of consumers," states were not required to actually share their policy making power with consumers. Consumers at best operated in an advisory capacity. The language which appears in Title VII of the 1978 Act is considerably stronger in this regard, for now consumers must be given a place in policy decision making. They are to be "substantially represented" on the boards and among the management and staff of independent living centers created and supported by funds appropriated by the Congress.

One must keep in mind that our recent legislative success in terms of architectural barrier laws, mandated special education, nondiscrimination requirements, and independent living were in large measure the direct result of the politics of confrontation and activism on the part of organized consumer groups. These groups and individuals are not now likely to passively relinquish all policy authority to professionals and their agencies.

In every meeting I have attended with national consumer leaders, participation and control have been a prominent, if not the most impor-

tant concern. Most consumer leaders feel that their participation in decision making and their control of independent living centers is fundamental and basic to the very definition of independent living; i.e., it is by, about, and for handicapped people themselves. Professional providers and administrators need to be aware that consumers regard our willingness to share power and authority as the "litmus test" in terms of our genuine belief in independent living. A period of conflict, accommodation, negotiation, and compromise may be anticipated as the major actors go about the business of translating law into workable policies and procedures.

CROSSROADS CARE ATTENDANT SCHEME TRUST*

Dr. Richard Hudson-Evans, Founder and Trustee
Crossroads Care Attendant Scheme, England

What is it? What are its aims? How did it start?

It has long been agreed in my country that the chronic sick and elderly are better cared for at home than in institutions. The reason this ideal of home care is not being achieved is that none of the statutory care support systems are aimed at giving active support to the care-giver in the home, but confine their efforts to those being cared for.

The statutory services (community nurses, bath attendants, home helps, health visitors, etc.) call at times and on days that suit their particular organizations, and these do not necessarily suit the wishes of the family being cared for. These services have a day to fill and their round is, no doubt, organized in the most economical way. One patient is bathed and got up at 8:30 AM whereas another will be bathed at 4:30 PM, whether he or she likes it or not.

Our organization aims at delivering the service at the times convenient to the families concerned, even if the hours are considered unsocial. We do not aim to impose methods of care on these families, but carry out their wishes. Neither do we usurp the work of the statutory services, but supplement it by providing our support at times when the statutory services are not available.

The one situation that fills both care-giver and the person being cared for with dread is what would happen should the care-giver be ill and unable to cope? Crossroads allays that fear by being available to take complete charge of the person being cared for until the care-giver is restored to health.

By giving the care-giver regular time off, they are better able to cope, especially if they can get away for a short holiday on their own.

Thirteen percent of 300 families being visited by Crossroads are helped so that the care-givers can continue working, thus saving them from retiring early or going on the dole.

The care provided by Crossroads can enable a person to be discharged from the hospital when no more medical treatment is needed.

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*This paper is a condensed version of the original.

How Crossroads Works

The great advantage is that each of the 18 schemes now in operation and the six more about to start (making 24 in all, so far) is autonomous and flexible in the times the service is required and provided.

A steering committee is formed to raise the money, and when finances are settled, the steering committee becomes a management committee that is totally responsible for the local scheme.

The lynch-pin of a Crossroads unit is the coordinator. This is a part-time post of some 20 hours a week. His or her job is to manage the team; interview all families referred by doctors, welfare workers, district nurses, or personal recommendation; visit and assess the need for help; if agreed, allocate a care attendant; act as confessor/auntie, shoulder to lean on, and support to all the care attendants.

The care attendants are chosen by the coordinator and the management committee. We have been very insistent that the applicants have the right motivation for wanting to care for others. They are given basic training in washing, bathing, bed-making and changing, prevention of pressure sores, and also the ethics of home visiting. Community nurses are not allowed to do domestic work; home helps are not permitted to undertake nursing duties--the care attendants will do either or both as needed. They undertake all the tasks normally done by the caring member of the family and choose their own times of availability for work, so the service is highly flexible. The care attendants are paid by the hour, supplied with overalls, and reimbursed their traveling expenses.

How Crossroads Started

Crossroads originated when the concept of caring for the caregiver was written into the soap opera Crossroads television series when I was medical advisor to the program in 1972-73. The need for the scheme was shown in the story line, and the method of solving the problem was illustrated. As a result, mail came flooding in from disabled families asking for such a scheme to help them, to such an extent that Associated Television Directors were approached for £10,000 to get a pilot scheme on the road for two years. This was freely given and the first scheme was started in Rugby.

After some 18 months, the scheme was working very successfully and the trustees approached the Department of Health & Social Security for aid to keep it going.

Funding

There have been various methods of financing the local schemes:

1. Joint funding between the director of Social Services and the Area Health Authority. We have had much encouragement from many directors of Social Services up and down the country.

2. Local fund raising undertaken by individual committees.

3. National fund raising to pay for the headquarters organization.

NATIONWIDE TRANSPORTATION SERVICE: A SWEDISH EXPERIMENT*

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The National Association for Disabled Children and Youth, Sweden

The handicap movement in Sweden has for a long time claimed that disabled people should be able to travel further, including across county borders. At their arrival or during their stay, they should be able to use the local transportation service in the place they are visiting. This we speak of as the nationwide transportation service.

Nationwide Transportation Service

In 1979, the Swedish government assigned 60 million Sw.Cr. (17 million Canadian dollars) for a three year trial period. A special committee was created to draw up rules and to manage the operations. This committee has a unique constellation of representatives: one from the Swedish union of local authorities, one from the government Ministry of Transport, two from handicap organizations, and one unbiased chairman.

Who Can Use the Service?

The first principle to decide was whether to offer an unlimited number of journeys for a small group of people or a limited number of journeys for a larger group. The committee chose, at first, not to limit the number of journeys.

The next principle concerned which groups were to be allowed to travel. Instead of listing the categories (groups), we concentrated on the difficulties of traveling. The resources available, under all circumstances, require a critical and rather narrow choice where only severely disabled persons come into question. The overall difficulty in making a longer trip is the crucial point.

The local authority examines the need for and issues the permit for the nationwide transportation service. This insures the necessary link between the municipal and nationwide permits.

Who Pays What?

An important question concerns the fare to be paid by the disabled person himself. The committee decided that this should be equiv-

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*This paper is a condensed version of the original.

alent to a tourist class train fare and that all additional costs be paid by the nationwide transportation service. In other words, additional costs caused by being disabled are the ones to be covered.

When Can It Be Used?

The nationwide transportation service is to be used for recreation and other private purposes. When applying for this service, the reason for travel is not questioned.

The journey should not be too short, as this would be a waste of a limited resource. With few exceptions, the shortest journey should exceed 60 miles. Obviously, the trip must go outside of one's own municipality. Sweden is a long country. From the south to the north, the distance is approximately 1,200 miles. Thus, very long trips are sometimes necessary.

Normally, a disabled person can use public transportation for the trip. Airplanes and trains are used the most. But even taxis or special vehicles can be used.

A disabled person in need of an assistant will have the fare for the assistant, but only the fare, covered by the government grant to the nationwide transportation service. The assistant has to be arranged for by the disabled person himself.

A crucial issue is the right of the disabled traveler to use the local transportation service in the municipality to which he has traveled. An agreement has been made among all municipalities in Sweden that a permit for the nationwide transportation service also includes the right to use the local service in the visited municipality. The traveler's own municipality will bear the costs in accordance with the regulations of the municipality that is visited. The regulations vary quite a lot from place to place.

Practical Administration

We have engaged a Swedish state-owned travel agency, well-represented throughout the country, to care for the practical administration of travel documents and to keep the necessary contacts with the municipalities involved. These municipalities have to be informed about the traveler's arrival and the local transports he might need.

The Committee's Work

All decisions made by an issuing authority, positive or negative,

are collected by the committee and regularly evaluated. Of special interest are the rejected applications and the practice that develops in the issuing of permits. This operation is computerized.

Why Have a Nationwide Transportation Service?

Two fundamental principles have been expressed in our work. A social aspect governs the rule that a handicapped person should never pay more for travel than a person without a handicap. One's handicap should not force one to a higher level of cost.

The second principle is that it is necessary to build up a special service system only because of the shortcomings of the ordinary public transportation system. When the public transport system is fit for accepting all types of handicap, we shall of course drop this second principle. (One can only guess how many centennials that will take.)

Will It Work?

It is an interesting experiment that now has started. We, in the handicap movement, are of course especially involved and our expectations are high. But we are also realistic people and know that the financial resources are limited.

HIGHER EDUCATION OPPORTUNITIES*

Kalle Könkkölä, Representative
The Educational Organization of the Disabled, Finland

Broader discussion of the education of the disabled has only recently begun. Until the present, the principle has been to exempt physically disabled children from formal schooling in order to avoid subjecting them to excessive stress. Nowadays, however, this is considered a deprivation of the right to learn. People were also of the opinion that the disabled only needed a short period of training leading to a vocation. This is partly true even today, since we are still at the discussion stage and there has not yet been any decisive change in policy. As far as education is concerned, the disabled are still in an inferior position.

Segregated Teaching

In recent years, the only alternative considered has been based on segregated teaching. With a slight element of exaggeration, we could describe the life span of a disabled person as follows: special day care, special residential school, special residential vocational training school, special hall of residence, and special transport from there to a special sheltered job with an especially small salary.

Each one of the above-mentioned institutions was originally thought to be in the best interests of the disabled. Nevertheless, there is good reason to ask whether they are always necessary and on what grounds they are used.

If we take the case of a disabled child who has lived his life in the above-mentioned way, it can be seen that he has been through an extremely efficient process of socialization. The later a person breaks free from that process, the more difficult he will find it to integrate into normal society, and the greater the future need for segregated special education.

Special teaching is needed, but it must be directed in a new way to insure that everything possible is done to achieve integration. Without integration, society is not normal, and the disabled do not enjoy a position of equality with others.

The fact that special education lags behind and is almost in crisis is mainly because the position of the disabled has changed as

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*This paper is a condensed version of the original.

society has developed. A group of people who formerly were the target for passive care, research, and teaching have started to demand the right to determine their own affairs. This is something some of the special teachers find hard to accept and to understand.

Activities by the Disabled Themselves

KYNNYS (The Threshold), an educational policy organization, was set up in Finland in 1973 to improve the conditions of study for the disabled and to raise the level of education among the disabled through an interest group. The following are some of the principles involved in the activities of the Threshold.

Our basic assumption has been that membership was open to all, both those with disabilities and those without. We consider it very important that people with different disabilities work together toward common goals. Over the years, this approach has proved very successful. In seeking solutions to various problems, we can deal with matters in a versatile way, in any case, the number of the disabled in higher education is so small that no single group would be strong enough to act alone.

The Threshold is not merely a student organization, although disabled students naturally form the bulk of the membership. This is an important principle, because it prevents disabled students from being separated from the affairs of the disabled in general, disabled students nowadays being in a privileged position in comparison with other people with disabilities.

We do not arrange services ourselves. This is because we want to devote all our energies to the determination and elimination of shortcomings. If we tried to arrange services ourselves, we would tie up all our resources at one time in efforts to solve a single problem. We see it as our task to explain to others what they should do and what responsibilities they have toward the disabled.

The disabled are experts on their own affairs. In our opinion, it is important that those disabled people who are receiving a higher education and who are thus formally qualified should act in the interest of the disabled as a whole.

Raising the level of education for the disabled is a difficult and slow process. Clear results will not come without action on the part of the highest decision-making bodies. We have stressed the importance of presenting the aims of the disabled on as wide a front as possible and also attempted to offer workable solutions in each separate problem.

Experience Gained from Activity in Organizations of the Disabled

Through their own organizations, the disabled can use their influence to insure that the right to education is obtained. This has been our experience in Finland, but the disabled must show a great deal of determination and staying power, since results are not achieved easily.

A great deal is expected of the disabled, and we cannot trust promises. By this I mean that we must harp on the same points time and time again and present detailed demands.

In our experience, we must be very exact when we express our wishes and pay attention to even the smallest details, for instance, building a ramp, having telephones on a lower level, installing automatic doors, etc. Otherwise, we cannot be sure whether the final result will be satisfactory or not.

We must not give in on our demands. Compromises must be left to the decision makers. This guarantees that the decision makers can trust us and that the view of the disabled on the matter in question does not remain unclear.

Demands must be well founded. It is no use appealing to the emotions. We must refer to general civil rights and to the fact that these rights should also include opportunity. We must be able and willing to cooperate. Criticism without cooperation does not help for very long, since in matters concerning the disabled, one must ask the advice of the experts, the disabled themselves.

Nationwide Research

In 1975, a report entitled The Disabled in Higher Education was published under the auspices of the Ministry of Education. This has been the only report of its kind in the field in Finland.

A new research project is now underway, this time with the participation of the disabled themselves. The following tasks have been defined:

1. To determine the number of disabled students in institutes of higher education and in senior secondary schools and other institutes, their distribution in various fields of education, distribution by area and by disability, as well as the difficulties encountered in study.

2. To determine the position in working life held by those dis-

abled who have an academic qualification or qualifications from an institute of higher education, the difficulties they have encountered at their place of work or in the work itself, any special arrangements, and their reaction to these. In addition, attention should be focused on the job placement channels through which they obtained work.

3. To determine the part played by the labor authorities in placing the academically qualified disabled in work and the part played by other authorities in helping the disabled to manage at work.

4. To determine the part played by organizations for the disabled as employers and as developers of employment methods.

5. To make suggestions regarding how to secure the hiring and retaining of the disabled who have been educated beyond the secondary education level.

DIAL UK: DEVELOPMENT OF THE NATIONAL ASSOCIATION OF DISABLEMENT INFORMATION AND ADVICE SERVICES*

James I. Woodward, Development Officer/Ken Davis, Coordinator
Nat'l Assoc. of Disablement Information & Advice Services, England

Open information is the raw material of knowledge. Knowledge is the basic tool needed to participate effectively in any activity or social organization. The movement in the United Kingdom to provide a network of local information and advice services promotes the provision of free access to open information.

In the absence of open information, disabled people cannot effectively participate in their society. Few people at this conference would deny the need for such active participation and, therefore, the need to supply open information. We contend that the most effective way to disseminate such information is to provide it at the local level. Here, at the local level, free and impartial information can be given directly to anyone concerned with disability. This basic commodity is what the National Association of Disablement Information and Advice Services offers, *inter alia*, through its associated local groups.

Information Disability

A lack of information is a situation generally shared by most citizens in the U.K. We have no legislation like that in the U.S. or elsewhere that provides for free access to information. In Sweden, for example, hospital patients have the right of access to their case notes, as well as to ward meetings to discuss their case. Restrictive practices in the U.K. exacerbate the situation of physically impaired people who have specific information needs. The national association has come to recognize that the way such information is collated, presented, and disseminated--or sometimes deliberately suppressed--actually disables physically impaired people. Of course, this same situation affects many others, including people who are illiterate, those suffering from dyslexia or other communication or mental handicaps, and even those who have suffered at the hands of our under-financed, mismanaged educational system.

We have, therefore, developed a concept of "information disability" that breaks with the traditional medico-sociological models. This tradition is illustrated by its attention to the individual and his or

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*This paper is a condensed version of the original.

her functional impairment. The effects on the individual of the social organization within which he/she participates are largely ignored. To focus on the nature of our social organization produces a fresh perspective on our circumstances. The physically impaired person who vitally needs open access to specialist information frequently finds mystification instead of matter-of-factness, complexity instead of clarity, secrecy instead of salience, or ignorance where there should be knowledge. These facts are deeply embedded in our social relations.

As I have implied, to the extent that most people in the U.K. are denied access to open information, most people are disabled by it accordingly. But for those, such as people who are physically impaired, where access to specialist information is crucial to meaningful participation, there is a significant distinction. Information disability is a specific form of social oppression. In practice, it results in the disadvantage or restriction of activity caused not by the impairment of the individual but by the way we present or withhold information and prevent opportunity for full participation in the mainstream of social life.

Disability as a Social Phenomenon

This shift of focus towards society from the individual is not new. Within the U.K., the social definition of disability has been expounded mainly by the Union of the Physically Impaired against Segregation. In their booklet "Fundamental Principles of Disability" they state:

> *In our view it is society which disables physically impaired people. Disability is something imposed on top of our impairments by the way we are unnecessarily isolated and excluded from full participation in society. Disabled people are therefore an oppressed group in society. To understand this it is necessary to grasp the distinction between the physical impairment and the social situation, called disability, of people with such impairments. Thus we define impairment as lacking part of or all of a limb, or having a defective limb, organ or mechanism of the body; and disability as the disadvantage or restriction of activities caused by a contemporary social organisation which takes no or little account of people with physical impairment and thus excludes them from participating in the mainstream of social activities. Physical disability is therefore a particular form of social oppression.*

Two points arise from these definitions, one, that disability is extraneous from physical impairment, two, that disability is imposed upon the individual by the society which does not accommodate this situation.

Within the field of rehabilitation, the historical development from the policy of institutionalization of the physically impaired to that of an integrated care system within the community has, in its wake, a growth of services and provisions which are extremely complicated for the individual impaired person to comprehend.

Passage through the intricate network of health and welfare organizations is full of danger. One can so easily get lost or left up a blind alley or completely fall through the net.

The Growth of DIAL

This was the situation in 1976 that Ken Davis discovered for himself when he was living in an institution. He became aware of the additional problems caused by lack of information among his fellow inmates and users of the center. He realized that in the community it was even more likely that information disability would be prevalent among those isolated from contact with the center or other services. He, therefore, set about with others to establish a telephone information service specializing in matters related to physical impairment. Over a six month period, the idea developed more comprehensively to embrace the notion of a free, impartial, and confidential service of information, advice, practical help, and counselling to anyone, lay or professional, able or disabled, in the local community. DIAL Derbyshire was born, the letters standing for Disablement Information and Advice Line.

The service caught the imagination of others. It was by no means the first specialist information service for the physically impaired, but it came at a time in the U.K. of a general growth of interest in the subject. In October 1977, a seminar was held to explore and exploit this interest. The result was the beginning of a national network of DIAL-type services. By June 1978, a steering committee was elected from representatives of local DIAL groups to form a National Association of Disablement Information and Advice Services, now known colloquially as DIAL UK. Its aim is to facilitate the spread of a network of local services so that physically impaired people are not disabled due to lack of intelligible information and informed advice anywhere in the U.K.

At the same time a further committee known as DIAL Information was set up to coordinate up-to-date and accurate information necessary to local services to operate efficiently.

These developments culminated in the appointment of a development officer and the opening of a national office in Derbyshire, England, to cover the whole of the United Kingdom.

The future of DIAL UK lies in the growth of the network of local groups. It is essential that disabled people actively participate in these groups and that the groups are independent and autonomous. The development of a democratic regionalized structure insures a service of high caliber by the constant appraisal of minimum standards through the regional study days and conferences. Cross-fertilization of ideas is not only maintained through such meetings but by means of a house journal that channels the multiplicity of information sources into the DIAL network.

Future Plans

In the close future, there are plans to link every DIAL office to a central computer that can be regularly updated *pari passu* with information changes. Ready access will be by a simple telephone call to the computer and the required information will be received on a TV terminal situated in each office. The advantage of this system is that the inquirer has an interface with the computer and can therefore request interpretation of the information on the spot.

By using this system, called "Prestel," DIAL UK will be able to integrate its service with other information-providing services using the same system. In this manner, a general information service can accommodate the specific requirements of any individual, disabled in any form, in any sphere of life.

IV.
Consumer Participation: Social Implications of the Movement

Now that we have looked at the people, the groups, and some kinds of participation, it is time to analyze the social impact of the consumer/ disability movement. Bruce Landstedt from Sweden examines the influence that the handicapped have in society as a result of controlling their own organizations. Jim Derksen from Canada discusses the reasons why the disabled consumer movement has an impact upon rehabilitation services and what the impact may be. Edward Roberts from the United States talks about how society can be structured to allow for the integration of persons with disabilities. Frank Bowe from the United States analyzes the issue of representation of disabled and able-bodied people. Barbro Carlsson from Sweden examines the integration of the handicapped into the political system. Eunice Fiorito from the United States describes the issues that confront a handicapped person or a nonhandicapped person when they become the decision makers and policy makers in government. Chapter 5 will look at this growing social movement from an international perspective.

THE INFLUENCE OF THE HANDICAPPED BY MEANS OF THEIR OWN ORGANIZATIONS

Bruno Landstedt, Executive Director
The Swedish Association for Neurologically Disabled, Sweden

We define handicapped as meaning people who, because of physical or mental reasons, encounter considerable difficulties in their daily lives. Consequently, this definition does not limit the extent of the concept of handicap. It is impossible to describe or define the handicapped according to the nature and reason for their handicap. It is important to distinguish handicap from injury or illness. A handicap constitutes the difficulties, sometimes impediments, individual people have to face as a result of an injury or an illness.

The difficulty or impediment that constitutes the handicap can be reduced or disappear entirely if steps are taken to change the situation of the individual either wholly or partly. That is to say, a handicap is a relative phenomenon. You are handicapped in relation to something, for example, your home, your place of work, or on a journey. The same person can be handicapped in some circumstances but not in others. Persons with the same injury or illness can have quite different handicaps depending on their environments. One person can be severely handicapped in a certain situation, the other not at all, because his surroundings are adapted to his functional limitations. Therefore, a handicap is not unchangeable. Both changes in the person and in his environment can alter a handicap, reduce it, or increase it.

Handicap affects many people. It not only influences the position of the handicapped person but also that of parents, children, and other relatives.

The possibilities for the handicapped to influence and have an effect on their own situation vary widely according to the cultural, social, and economic conditions of the countries in which they live. This means that, in my opinion, there is no general solution to the question as to how the handicapped themselves can have an influence through the organizations that represent their interests.

Nobody should object to the statement that there is a societal need and a personal need for the handicapped to have an influence on the rehabilitation process as well as on the development of society. It is, however, only when these common interests are gathered as one objective that the demands can be brought forward. Individual requirements are transformed into general claims, and individual experience is transformed into general knowledge. The expression "we demand" is stronger than "the handicapped demand." This is what should happen in a handicap organization.

After this introduction, in which I have tried to describe how I look at the concept of handicap and what should be the basis of a handicap organization, I am fully aware that my approach will not necessarily be shared by everybody else. When we speak of handicap or handicap organizations, we mean different things according to which terms of reference are applied. Generally speaking, a handicapped person is someone who must be taken care of, someone who needs to be looked after. He or she is the receiver of our care.

In order to explain what I mean by "influence of the handicapped by means of their own organizations," I shall try to describe developments in Sweden. I do not do that because we have in any way entirely solved the problem or because I wish others to accept our way of looking at handicap questions, but because I would like to inform you of the development that has led to my definition of handicap and what we would expect from a handicap organization.

The Historical Perspective

In the old Swedish agricultural and handicraft society, handicapped persons were cared for by the family and the local community. However, through the urbanization and monetary economy that developed during the 19th century and through growing industrialization, the possibilities of caring for the handicapped by the family were changed.

Particularly among the poor in towns, the situation became very difficult for the handicapped. The possibilities for supporting a handicapped family member were very small. Many people became handicapped from the poor living conditions prevailing in towns and other densely populated areas. Tuberculosis was a very common disease among the working classes, and many suffered permanent injury and became handicapped in the factories and workshops owing to the very miserable working conditions.

Society was badly prepared to look after and help these groups of handicapped. As a result of this, the first special institutions for caring for the handicapped by society were organized in the latter half of the 19th century.

The basis of a handicap policy began to develop, and the first handicap organization in Sweden appeared at the end of the 19th century. Society's outlook upon handicap questions was strongly tied to the Christian idea of charity.

However, at the start of the 20th century, certain tendencies were noticeable showing that the ruling classes had observed the socio-

political problems of the handicapped that resulted from growing industrialization. The help and care then offered was mainly within closed institutions.

Changed conditions for the handicapped were brought about very slowly, and it was not really until after the Second World War that anything important began to happen. Sweden had been saved from the war but was influenced by the methods of rehabilitation and treatment that were applied in the rest of Europe, primarily for those who had been injured in the war.

When Sweden had a boom in the fifties and sixties, demand for labor increased. This was one of the reasons for the great interest in getting handicapped people out into society and into production. In order to realize the dream of a welfare society, the Swedish labor market required more people. If living standards were to improve, more handicapped people and women had to be encouraged to join the labor market. Immigration into Sweden had also to be increased.

At the same time that it was found that the handicapped could be an asset to the labor market, questions related to handicap began to become of general interest to politicians. Socio-political questions were brought into the foreground.

Development of the Handicap Organizations

The problem of the handicapped was pursued by society for a long time from the Christian point of view, and it was individual persons who stood up for them. Apart from a few organizations that were founded before the turn of the century, it was not until 1920 that the handicapped started forming their own organizations. These were, however, primarily associations of friends and patients of institutions and hospitals. It is interesting to note that the reason why many handicap organizations were named after diagnoses such as MS, polio, lung diseases, etc. instead of the functional handicap was that the organizations were often started among patients at hospitals and institutions.

It was during the post-war years that the major period of organization occurred and interest began to be shown in the community outside the institutions. In the fifties and sixties, an increasing number of groups of the handicapped began to form their own organizations together with relatives and others concerned.

For a long time, rehabilitation was the prime interest; one wanted to give the handicapped individual aids that were as true to life as possible or to adapt only those parts of the environment that were es-

sential to enable the handicapped to work and live. It was the individual who had to adapt himself to the existing environment.

From having been supportive and friendly organizations for the handicapped, the handicapped within the organizations started more and more to formulate their claims and to demand "one society for all." (The society belongs to us all.) The handicap organizations had come to be welfare organizations for handicapped people that could be compared to professional organizations. More and more handicap organizations formulated their joint requirements in the form of action programs focused on different sections of society. In order to be accepted as a handicap organization in Sweden today, it is vital that the handicapped themselves have a decisive influence at all levels of the organization.

Swedish Handicap Ideology Today

For a long time, a handicap was seen as related to an illness, injury, deformity, or some other condition. Efforts had to be directed at the individual himself. As was said in the introduction, we now look upon a handicap as a relationship between the individual and the surrounding society. Under those circumstances, a handicap is no longer a static conception but can be related to a specific situation. With such an outlook, it becomes possible to considerably reduce the degree of a handicap or to limit the consequences of a disability.

A child or someone using a wheelchair who cannot reach the button of a lift is handicapped in that situation and must have outside help. If, however, the buttons are placed in such a way that both the child or the person in the wheelchair can reach them, then they are not handicapped in that situation.

Efforts made for the handicapped should aim at their being able to join into the community that society has formed and to enable them to live like everybody else. Society, both the exterior physical environment and the activities performed in society, should be accessible to the handicapped. The aim should be to avoid, as far as possible, creating an activity intended only for handicapped persons.

The foundation for work in the handicap sphere can be summarized in the terms of normalization and integration. Normalization is the controlling concept and means that the daily conditions of the handicapped should be made as similar as possible to those of other citizens. Integration describes the means that are essential to achieve normalization. Integration can be general, covering widespread actions, or it can be aimed at special groups or environments.

Influence of the Handicapped

If the handicapped are to achieve a real influence over their situations, it is essential to look upon them as equals. One who is dependent on other people's help is often treated as a child. People speak over his head or to an accompanying adult. The same is very often true with regard to a person in a wheelchair, people address themselves to his companion and not directly to the handicapped person.

It will take a long time before prejudice and negative attitudes are changed and before the handicapped will be recognized as equals, persons capable of making their own decisions. As long as people continue to see the handicapped as patients to be cared for and looked after, they will never be able to partake fully and achieve equality in society.

From sheer concern for their child, parents of handicapped children often tend to over-protect them. At the same time, it must be a safe feeling for these children to have somebody looking after them who cares for them and who knows what is best. This same attitude is felt by those who have long been nursed in an institution. Experience in Sweden shows that this frequently leads to isolation and a passiveness that for many will be difficult to overcome. Therefore, social training and gradual adaptation to society outside the institution or the safe family community is required. Rehabilitation consequently has to be aimed in two directions, partly towards the handicapped and their requirements and partly towards society.

The handicapped person has the best expert knowledge of his handicap. It is difficult for an outsider to put himself into the position of the handicapped. To sit in a wheelchair for just an hour or to be blindfolded is not the same as to be disabled or blind.

If the handicapped organizations only exist <u>for</u> those who are handicarped and do not consist <u>of</u> those who are handicapped, the rule of "looking after" will be difficult to avoid. In my opinion, it is important that the handicap organizations leave a decisive influence to those who are themselves handicapped; then handicapped and nonhandicapped can jointly strive to realize the goals of the organization. By the handicapped themselves being active, they can illustrate in a practical way the difficulties that exist in society, and the nonhandicapped can learn from their relations with the handicapped.

Independence can be aimed at most eagerly by those who have been dependent. This is the case for the handicapped in their fight for their rights. He who fights for his own sake does not forget the fundamental goals nor does he compromise about them. This is the reason why

the nonhandicapped should not direct the handicapped in the work of their organizations, but only give them their support. The responsibility is after all shared by us all.

Only through the "influence of the handicapped by means of their own organizations" will it be possible during 1981 (the International Year of Disabled Persons) to start the realization of equality and full participation.

THE DISABLED CONSUMER MOVEMENT: POLICY IMPLICATIONS FOR REHABILITATION SERVICE PROVISION*

Jim Derksen, Executive Director
Coalition of Provincial Organizations of the Handicapped, Canada

The individual who becomes permanently physically disabled in Canada today finds himself in a bewildering, new and different world: a world where he is no longer responsible for his family, for his personal financial needs, for his behavior, for most of the things he had been responsible for as an adult person in society. Gone with these is his right to expect equal social acceptance as a responsible adult human person: the right of political and economic involvement in society, the right of access to public buildings and programs, the right to equal access to private services and facilities, the right to travel freely, the right to choose his employment and associates, the right to sexual expression, and so on. All are gone, or at least diminished.

He finds that he is expected to play a very specialized recipient role in relation to charitable givers. In place of the dignity of self-sufficiency, he is expected to exhibit a passive gratitude for what others choose to give him.

This same person is expected to accept the permanent nature of his disability despite the fact that in a thousand ways each day society and the helping professions that cluster around him reinforce the idea that he is in fact sick and expected to get better.

What will occur if this disabled individual does not accept the arrangements that have been made for him? What will be the result if he demands that the permanent nature of his disability be accepted by those around him and by society; if he says he is not sick and should not be treated as a sick person? Who can predict the shape of things to be if he demands to be held responsible for all the things that adult people are expected to be responsible for in this society; and what will happen when he demands his right to participate in every aspect of society?

The Emerging Consumer Ethic

The consumer ethic that is now emerging as having some impact on policy for rehabilitation service provision is the first ethic to be defined by the disabled person himself. The disabled person is the poor deserving cripple under the volunteer charity ethic as defined by the giver of charity. The disabled person is the "patient" under the medi-

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*This paper is a condensed version of the original.

cal ethic as defined by the medical practitioner; similarly, he is the client under the professional ethic as defined by the professionals. Only under the consumer ethic does the disabled person take an active role in defining the ethic that influences policy.

The consumer movement and its organizations are the collective expression of the growing consumer ethic awareness in individual disabled people. Structurally, this movement well-suits the independence motif it carries. The medium fits the message, as Marshall McLuhan would have it. In the sense that disabled people are joining other minorities in pressing for rights and an improved environment, the structures follow the community model and so also suit the integration motif; however, this is not entirely so. There is a necessary contradiction between the call for integration and the method of achieving this by grouping together in organizations made up of and controlled by disabled people only and this is a problem.

The recent ascendancy of the disabled consumer ethic is due to a number of causes. A general disillusionment with health care systems and professionals, together with rising costs associated with these, are part of the cause. The 1960s' legacies of social activism and consciousness with regard to civil rights and discrimination in various forms must also be credited as part of the etiology of the emerging consumer ethic and its influence on government policies and programs.

The recipient who defines himself as consumer is no longer a passive recipient but rather an active consumer participating in the decision making about the production-provision/consumer relationship. The consumer claims as a right this active participation in decision making.

Consumer Impact on the Charity Ethic

As the charity ethic has greater impact by far upon the policies and programs of privately-funded service providers, the consumer ethic has least impact here. The very idea of the equality of the consumer with the provider in the provider/consumer relationship is completely contradictory to the underlying assumptions of the giver and recipient role expectations of the charity ethic.

The consumer ethic is nominally recognized in the perverted form of token representation by disabled persons on boards of directors ostensibly governing privately-funded and cross-funded service providers. These individuals are usually chosen to support the charity ethic role model of the disabled recipient as childlike, passive, apolitical, asexual, in need, and suffering a poverty of opportunity and resources. Their presence serves a twofold purpose.

First, it subconsciously enforces in the mind of the giver the abnormality of the disabled person, the difference or gap between the able-bodied giver and the disabled recipient, and the need to isolate disabled people to satisfy the avoidance and fear reactions they evoke. Second, their presence acts as a camouflage against those who would criticize the rehabilitation service provider and associated charitable givers.

Consumer Influence on Government

The consumer ethic plays a more important role in determining the policies and programs of government-funded rehabilitation service provision. It also plays a most important role in influencing government to open up access to a variety of community services and opportunities such as housing, employment, recreation, etc. outside of the rehabilitation context. The phenomenon of consumer ethic influence in both these areas deserves general discussion before we refocus on rehabilitation service provisions. This phenomenon is, in Canada, only about one year old. It is, however, a central and significant trend that is gaining momentum.

The consumer is aware of his role as consumer-citizen and his impact upon government legislation and policy development in which he claims the right of access. As there are a growing number and, potentially, by self-definition a massively greater number of consumers of rehabilitation services and mainstream community access than providers, the politician is most receptive to input from the consumer ethic through organized consumer groups. It follows that the bureaucrats are also receptive to such input.

The independent living objectives of the disabled consumer movement are also most attractive to the current mood of government as they are related to economic savings to society at large. Independence is obviously an economic savings. Integration can be shown to be so by cost-benefit comparisons of separate programming against the more cost-effective (over the long term) modifications to existing community services, programs, facilities, and so on to make them accessible and available to disabled persons.

The consumer ethic's emerging impact on access to services ordinarily available to the public is taking several forms in relation to government. On the one hand, the movement's active lobbying role with reference to particular community service areas, such as transportation and access to public employment, is resulting in representation from consumer organizations on advisory boards to government departments responsible for these areas. Hand in hand with this emerging advisory influence is the movement's central lobbying thrust for comprehensive hu-

man rights legislation. This human rights thrust, when successful, will have significant implications for equal access to all community services provided through or controlled by government.

In the meantime, government is actively soliciting consumer input through research contracts with disabled consumer movement organizations and through government funding of policy formulating conferences in the consumer movement to address particular subject areas such as transportation and employment.

Consumer Influence on Government-Funded Rehabilitation Services

Refocusing on rehabilitation service provision directly funded by government, such as rehabilitation centers/hospitals and nursing homes, we find consumer ethic influence just beginning. While the consumer movement has been active from the early 1970s in seeking access to community services, it was not until the fall of 1979 that rehabilitation was addressed in terms of national policy development. This important topic was avoided by the movement until this late date for the strategic purpose of establishing in the minds of disabled people and society the place of disabled people outside of the rehabilitation context. It was first necessary to establish them in the role of consumer citizens calling for access to community services.

The consumer movement's perceived need to draw parameters around the concept of rehabilitation and identify itself as a full participant in society outside of the rehabilitation context continues to place some limitations on the movement's involvement in this area. The disabled consumer movement, however, is supportive of a distinctly separate patients' rights movement. Many individuals within the disabled consumer movement are active in patients' rights organizations, and these will become an important vehicle for influencing rehabilitation policies.

The Open National Conference on the Parameters of Rehabilitation, initiated and coordinated by the Coalition of Provincial Organizations of the Handicapped (COPOH), was held in early May of 1980 in Vancouver. This conference delineated some disabled consumer movement policy directions in the area of rehabilitation that will be described later in the paper.

Consumer Influence on Cross-Funded Rehabilitation Services

Cross-funded service providers are those who have both government and private funding. They represent the most common form of rehabilitation service provision outside of that provided directly by government. Consumer ethic impact on the policies of cross-funded rehabilitation

service providers has taken a variety of forms. Perhaps the most fundamental impact has been the movement's efforts to open up access to regular community services. This positive thrust has threatened and damaged the image of these service providers as taking care of all the needs of disabled people. The growing influence of the consumer movement on government and the public mind has necessarily weakened the influence and authority of these service providers.

Cross-funded service providers have exhibited three reactions to this. The initial reaction, which was most unsuccessful, has been to use such covert influence as these providers have on government and private funding sources to deny resources to emerging consumer groups. This was often accompanied by offers of assistance and resources to disabled consumer activists and/or their organizations in and under the structure of cross-funded service providers. When these offers were refused, there were often charges that disabled consumer leaders were maladjusted, unaccepting of their disability, or even mentally and psychologically unbalanced or ill because of their disability. Consumer movement activists were accused of being radical or militant. Because this initial resistance reaction has for the most part failed, these service providers have begun to develop a new strategy that is potentially more dangerous to the disabled consumer movement.

This more recent development is the accretion of community development service programs as one or more among the many programs offered by these providers. These community development programs develop organizations of disabled people that take the name of the consumer movement without incorporating the movement's fundamental values, philosophies, and perceptions. They are often developed by the provider's community development worker in the context of therapy or rehabilitation.

These artificial citizens' groups, supported/controlled by the provider's staff, do not incorporate the real leadership development found in true disabled consumer organizations. They sometimes take the form of associations that also serve the provider in private fund-raising efforts. This further degradation and exploitation of disabled people, mocking as it does their efforts to achieve some self-determination and independent living objectives in society, is perhaps most dangerous because, potentially, it may result in confusion in the public mind as to the true identity and desires of the disabled population.

The third reaction of the cross-funded rehabilitation service provider to the growing consumer ethic is most rare, that being the acceptance of the proper place of the individual consumer as a participant in the decision-making processes of the provider and acceptance of the consumer organization as monitoring, from an independent organizational position, the effectiveness of service provision.

The most hopeful development in meeting the objectives of the emerging consumer movement is the capacity and willingness of disabled individuals, having gained political awareness and skills within the movement, to offer themselves as community-minded and responsible volunteers for nomination to the boards of directors of cross-funded service providers. As they participate as individuals on these boards, the autonomy of the consumer organizations from which these individuals originate is not infringed. It is also politically most difficult for any service provider personnel, who unfortunately may feel threatened by active disabled participation at the board level, to actively campaign against the election of disabled individuals offering themselves for these positions.

Because of their often highly democratic forms, the constitutions of these service providers can provide good access to disabled consumers who wish to be involved in the decision-making processes of the service provider at the board level. The present large size of these boards of directors means that small groups of disabled individuals offering themselves for nomination will remain a minority component of the board when elected. This, however, should not be an impediment to their influence, as the remainder of the board members are usually community volunteers with goodwill toward the disabled population and little vested interest in the agency status quo. They will prove generally amenable to policy input from the disabled members.

The biggest task faced by such disabled individuals on cross-funded service provider boards of directors will be to reorientate and strengthen the boards to the point of taking on the legitimate and necessary moral and legal responsibility for policy direction of the cross-funded service provider which is the board's. This will not be a simple task as these boards have accepted for the most part their restricted role as fund raisers and as a mechanism for community/political credibility and influence for the cross-funded service provider.

Strengths, Potential Benefits, and Appropriate Roles of the Various Ethics

I have until now emphasized the problems and difficulties posed by the volunteer charity, medical, and professional ethics. I have also indicated at least one problem in the consumer ethic as it relates to rehabilitation and the achievement of independent living goals. I would now like to identify and emphasize the positive characteristics of these ethics, or, if I may use the term loosely, "rehabilitate" them.

The Volunteer Charity Ethic

The volunteer charity ethic originates essentially and ideally from goodwill and generosity of self. As such, it is clearly a virtue

and is so recognized biblically. In its true form as a virtue, it is potentially present throughout humanity and has great potential strength and benefit for society. Its appropriate role in reference to our topic is chiefly in able-bodied individuals' acceptance and understanding of the unique needs and resources of their disabled fellows. In disabled individuals, it must be present in acceptance and understanding of the experiential limitations that limit knowledge, and so capacity, of their able-bodied fellows. Expression of the true spontaneous volunteer charity ethic by individuals would obviate many of the problems faced by society in regard to disablement today and would eliminate the need for many forms of institutionalized service and help.

The biblical parable of the widow's mite illustrates a most essential characteristic of true charity, which is that charity does not seek gain for the self, such as personal feelings of magnanimity, self-sacrifice, etc., but rather gives anonymously for the sole purpose of giving.

Although the collective expressions of the volunteer charity ethic have been seen to be generally most perverted from this ideal, it is possible that the goodwill and giving of self implied by true charity for humanity can be expressed collectively in a positive manner. This has been demonstrated by some consumer movement organizations, in equal partnership with business and private sector service organizations, by engaging in project activities that are of general benefit to society. Such partnership activities of general societal benefit serve primarily to enhance the image of disabled people as valuable, participating, and contributing members of society, while at the same time, they generate resources to solve common societal problems presented by the contemporary position of disabled people in society.

The Medical Ethic

The medical ethic too has its original, essentially valuable motive, that of healing the sick. Most people are ill at one point or another in their lives and have need of medical help. Disabled people perhaps have a particular need for medical help inasmuch as disablements generally originate with disease or accident. Some forms of disablement also involve recurring bouts of illness or predictable requirements for medical help at various points during life. In this context, the medical ethic and its function of healing is very necessary and valuable to disabled people.

In its legitimate role of healing, the medical ethic must become aware of the full implications of the "sick role" it assigns to patients. This role's characteristic of relieving the sick person of certain responsibilities is also essentially a valuable one. It is obvious that

the healing process will be enhanced by relief from the stress of certain obligations and responsibilities. At the same time, this relief from responsibilities for the patient must not be carried on so far and for so long a time that the patient becomes unable to deal with and take up again his responsibilities after the restoration of health. The medical profession is beginning to realize this necessity.

The chief solution to the problems presented by the medical ethic in the achievement of independence and integration by disabled people is a realization that the attribution of the sick role to the disabled person is inappropriate. In addition, in designing and applying treatment, it is important that medical practitioners take into account the whole human personality and nature of the individual. Again, indications of this realization are presently being seen within the medical profession.

The Professional Ethic

The professional ethic, at its heart, has the essentially necessary understanding of the importance of knowledge, training, and experience. Its central and valuable objective is to achieve recognition and respect for this expertise from the public and especially from those who would benefit from it. With this objective fulfilled, they can most effectively apply their knowledge, training, and experience where and when necessary without interference. The value of this understanding and objective is indisputable.

It is fortunate that many in the helping professions are now beginning to realize that they can best help and apply their knowledge when the individuals being helped share in an understanding of the methodologies being applied. They must also be enabled to participate in decision making throughout the helping process and to participate in this process in an essentially equal manner.

The professional ethic must also understand the limitations of the knowledge it protects. By this, I mean specifically that professional practitioners must recognize the need for accountability to the community that provides them with the resources and wherewithal to practice. It is on behalf of this community that they are enabled to practice; this community includes disabled people as well as the larger community of which disabled people are a part.

The Consumer Ethic

A problem identified in the consumer ethic for the achievement of independent living goals by disabled people was the contradiction between the objective of integration and the methodology of banding to-

gether in consumer organizations made up of and controlled by disabled people. It is important, in my view, that disabled consumers recognize that society at large and the able-bodied people in it have interests in common with disabled consumers; that, in a sense, all of society consumes or is impacted upon by the way services are provided for disabled people.

This means that the membership requirements of disabled consumer organizations will in many cases need to be modified to allow participation by able-bodied people. This must always be under the condition that able-bodied participants understand the importance of disabled leadership and the priority of the disabled person's perspective and opinions, based as they are on direct experience of problems to be solved.

Membership criteria are gradually being changed to allow full participation by able-bodied persons who share a basic understanding of the disabled consumer perspective. This is because an increasing number of able-bodied people understand the philosophies, values, and perspectives of disabled consumers, and because disabled individuals have gained the confidence and abilities through participation in disabled consumer organizations.

Some Predictions of Future Policy Directions

The most general policy implication of the disabled consumer movement for rehabilitation service provision is the restriction of the rehabilitation concept to the treatment mode and the resulting shift of certain functions away from rehabilitation services to general community services and independent living services.

Independent living services are those that are uniquely required by the physically disabled individual in order to maintain an independent lifestyle in the community. They are distinct from what I term general community services inasmuch as they are not required by able-bodied people. They are also distinct from what I term rehabilitation services inasmuch as they are not a part of treatment to remedy the effect of disablement, but rather are services necessary for the maintenance of independence and integration of the disabled individual after the completion of rehabilitation treatment services.

General Community Services

More physically disabled Canadians will be represented in the entire spectrum of commissions and boards that manage and direct general community services, i.e., school boards, hospital commissions, arts

councils, transportation commissions, housing authorities, parks boards, public service commissions, and so on. Just as today there is a societal expectation that women be represented on these, tomorrow there will be a general societal expectation that disabled people too be represented. This will naturally result in general understanding of the need for and means of equal opportunity for access by disabled people to all the variety of general community services.

The disabled consumer movement will continue to lobby for legislative change at all levels.

Confrontation tactics and absolutist ideologies will be avoided by the Canadian disabled consumer movement. Architectural and communications system design modifications will be promoted as being more usable by all people rather than as necessary for accessibility by disabled people alone.

Public transportation will become more accessible and usable by disabled Canadians. ... Public housing of all kinds will become accessible for disabled Canadians. ... Disabled people will receive their public education together with nondisabled people.

Preferential hiring for disabled Canadians, on the same social need basis as "veteran's preference," will be implemented by public service commissions at provincial and federal levels for limited time periods.

In the area of recreation, camping and park facilities will quickly become accessible.

Independent Living Services

It will be discovered that the unique needs of disabled people beyond the rehabilitation treatment process are more related to equality of opportunity, citizens rights, and the social problems of other minorities than to medicine and health. This discovery will result in direct programming from government to meet these unique nonrehabilitation needs of the disabled minority.

I will term the service providing unit for these direct services from government independent living centers. These centers will offer a broad range of technical aids and appliances that are disability but not health related. In conjunction with this, they will also offer engineering and technical services to modify household appliances, cars, and so on for use by uniquely disabled individuals. In addition, these centers will offer attendant care resources. Peer counselling services will also be offered, probably by contracting this resource from local

disabled consumer organizations. It is also likely that some basic legal counselling resource will be incorporated in its design. Hopefully, this will not in any way replace or duplicate community legal services.

These independent living centers will be managed by community boards made up of at least 50% disabled consumers.

Rehabilitation Services

More disabled individuals will volunteer to serve on the boards of directors of rehabilitation service agencies as well as hospital commissions and the like. Involvement of these disabled individuals in such positions of authority will provide more positive role models for staff providing rehabilitation services. Provider staff for too long have been exposed only to disabled individuals who, for a variety of reasons, reinforce staff expectations of disabled people as dependent and requiring assistance. Generally, more effort will be made and care taken to insure that rehabilitation personnel attitudes are in line with true rehabilitation requirements.

Generally, rehabilitation services will be redesigned and modified to provide the disabled individual being served with greater self-expression, self-determination, and general involvement in the rehabilitation service process. To some extent, this will be accomplished by a federal requirement for rehabilitation contracts, which will be negotiated between the rehabilitation service provider and the disabled individual concerned and will incorporate definite time lines with measurable objectives.

The patient's rights movement will continue to grow and require accountability from the rehabilitation service provider and health care system generally. This movement will continue to call for greater recognition of the rights of patients, including their right to self-determination and input to decision-making processes during rehabilitation.

FROM CHARITY TO INTEGRATION: A NEW FUTURE FOR PERSONS WITH DISABILITIES

Edward Roberts, Director
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Not so long ago, the prevailing attitude in the United States was to treat persons with disabilities as objects of charity. Organization after organization sprang up to "protect" various disability groups. These organizations were well-intentioned, but their emphasis on charity produced fear and segregation. There is a fundamental and basic flaw in treating any person as an object of charity. In the case of persons with disabilities, the consequences of such a characterization have been counterproductive. In order to enhance fund-raising efforts, some organizations portrayed persons with disabilities as weak and helpless. By doing this, the well-intentioned organizations reinforced a negative social attitude toward disability.

The existence of charities, furthermore, provided the major institutions in our society with a convenient excuse for not meeting the real needs of persons with disabilities. Government, the educational system, and business were able to avoid any meaningful responsibility toward persons with disabilities by simply deferring to the charities.

Challenges to the Charity Ethic

In the past decade, fundamental changes began to take place. The starting point for this change really began in the middle to late 1960s with the black civil rights movement in the United States.

The parallels between America's treatment of blacks and persons with disabilities were readily apparent. Separate education made no sense, whether it was based on color or disability. The denial of employment opportunity made no sense, whether it was based on color or disability. Simply stated, segregation on any basis made no sense.

In the late 1960s and early 1970s, persons with disabilities began to take control of their own lives. Our philosophical premise was simple: We have a fundamental human right to equal opportunity to participate in every aspect of our society.

In order to secure this right, we had to free people with disabilities from a patronizing and segregating society. The process of desegregation has gained considerable momentum in the past few years.

Changing Attitudes Toward Disability

One of our major tasks has been to change the general public's attitudes toward disability. As I mentioned earlier, American society

tended to view persons with disabilities as weak, helpless, dependent, asexual, and oftentimes as intellectually inferior. This attitude in turn fostered a negative self-image among persons with disabilities.

In the past decade, we have done much to dispel the myth that persons with disabilities are weak or sick. Persons with disabilities have participated and succeeded in every aspect of our society. Yet, there remains a great deal of ignorance in our society about people with disabilities. I believe that one of our greatest responsibilities is to educate our society about the strengths of persons with disabilities.

We need, for example, to educate the mass media, which all too often runs stories about a helpless, poor, handicapped person. That type of story is simply misleading and deceptive. We must provide the media with information about persons with disabilities who are successful doctors, lawyers, auto mechanics, computer programmers, etc. We need to help the general public understand that disability in and of itself is not devastating, and that a person who has a disability can live an active and rewarding life. We must do this not only for ourselves, so that we can gain the opportunities to fully participate in society, but also for everyone else. A Swedish study estimated that 60% to 70% of the general public will suffer major mobility-impairing disabilities during their lifetime. We need to help the people who will one day be disabled to come to terms with their fears and stereotypes of disability.

Changing Institutional Practices

Changing attitudes is only one part of our task; we must also work to insure institutional changes to correct the inequities in our laws and practices that effectively discriminate against people with disabilities and take away their hope and opportunity. In the last decade, the U.S. federal government has passed a series of laws which in the words of the then Secretary of Health, Education and Welfare "reflect a national commitment to end discrimination on the basis of handicap...and to bring handicapped persons into the mainstream of the American life."

Two of these laws[1] prohibit discrimination in preschool, elementary, and secondary education. The laws require (1) that a student with a disability, no matter how severe, be provided with a free appropriate education (2) that students with disabilities be educated with nondis-

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[1]The Education of the Handicapped Act (Public Law 94-142) and Section D of the regulations promulgated under Section 504 of the Rehabilitation Act of 1973.

abled students to the maximum extent feasible and (3) that evaluation procedures be improved in order to avoid the inappropriate education that results from the misclassification of students. These laws also establish safeguards to enable parents to influence the evaluation and placement of their children.

The importance of an integrated education cannot be emphasized enough. When I was 14 years of age and an aspiring athlete, I became severely disabled. I remember the doctors telling my mother that I would be nothing more than a vegetable.

Fortunately, our school system in Burlingame, California did not have separate schools for students with disabilities. The school system had to figure out a way to get me from my bed to rebegin my education. I had to overcome the fear of going out and having people stare at me because I was different.

Accepting Risks

I also learned that I had choices, and that to get anywhere, I would have to learn to take risks. One of the most obvious problems with patronization and segregation is that it shelters too many people with disabilities from learning to take the risks that lead to personal growth.

I remember when I was at the University of California and I fell in love, it became incredibly inconvenient to have to take an attendant with me. I had been told for years that I could not drive a power wheelchair because I was so severely disabled. But, I decided to take the risk, because I had a lot at stake. I crashed in the beginning, but then I learned.

Expanding Employment Opportunities

The federal government in the United States has also made it clear that discrimination in employment against persons with disabilities must end. Federal law, when fully implemented, will open up hundreds of thousands of jobs to persons with disabilities.

The key provision of these laws is the concept of reasonable accommodation. As we all know, work sites were historically designed by and for a population without disabilities and thus denied employment opportunities to persons with disabilities. In the future, employers will have to make reasonable accommodations to enable a disabled person who seeks an employment opportunity.

This concept is, perhaps, best illustrated by example. In the case of a deaf employee, it may mean the purchase of a TTY device, which is a teletype device such as those used by Western Union. In the case of a partially blind employee, reasonable accommodation may mean the purchase of a reading device. If an employee is in a wheelchair, the employer may have to widen the doors to accommodate the wheelchair.

These new laws against employment discrimination, thus, offer real hope and opportunity. For years, persons with disabilities could only look forward to a life which, in an economic sense, was entirely dependent on the welfare system.

Over the past couple of years, we have begun to work with business, labor, and government to create employment opportunities for persons with disabilities. For example, in the San Francisco Bay Area, a number of labor unions have integrated disabled persons into their apprenticeship programs. Giant corporations, such as Standard Oil, IBM, and Levi Strauss, in cooperation with the state rehabilitation program and an independent living program, are training and hiring severely disabled persons as computer programmers.

Full Participation

In addition to integrating our schools and work force, we must also insure that persons with disabilities can fully participate in all aspects of our society. For too many years, persons with disabilities were isolated from the mainstream of American society. Many of us were needlessly institutionalized; others were totally dependent on family or friends.

In the early seventies, we began to develop the concept of independent living. The first step toward independent living was the development of in-home supportive services.

Instead of being dependent upon a nurse or family member, we began to hire, train and, sometimes, fire our own attendants. We learned invaluable lessons and skills.

For example, I have probably hired and trained over 100 personal assistants in my 25 years as a person with a disability. This experience has taught me to be a good personnel manager. I have learned how to recognize people who have the right talents and qualifications for my needs. I have learned the art of constructing budgets that will maximize my return. I have learned to understand my needs and to communicate those needs to the persons I hire.

In California, we joined forces with senior citizen groups to convince the state legislature that it was far more humane and cost-effective to fund in-home supportive services than programs that perpetuated institutionalization.

One of the key elements of the program in California is that it places the responsibility on the person with the disability for the management of the program. The individual has the right to hire and fire attendants and to manage the money.

We have, thus, developed a program that not only enhances our right to live independently, but also eliminates needless levels of bureaucracy. We have also developed one of the most effective job programs in the state. Thousands of persons who were previously unemployed are now working as attendants.

Our second major initiative in the early seventies was the development of independent living centers. These centers provide the range of services that a person with a disability needs in order to effectively participate in society. The centers, which bring together persons of various disabilities, provide services such as peer counseling, job training and counseling, housing and attendant referral, sex counseling, legal assistance, and transportation and recreation programs.

The first center we created was the Center for Independent Living in Berkeley, California. It now serves as an international model. In Title VII of the 1978 Amendments to the Rehabilitation Act, the United States Congress recognized the need for independent living centers. Title VII requires the establishment of independent living centers throughout the United States. Although it will be some time before this act is fully implemented, it offers new hope to millions of persons with disabilities throughout the United States in terms of both social and economic independence.

Conclusion

As I noted earlier, the process of desegregating a society is neither quick nor easy. We still have a long way to go in making our public transportation system accessible to persons with limited mobility. We also must make more of our buildings and housing accessible. As in the past, we will face stiff opposition. We will be confronted with so-called cost-efficiency computations to "prove" that segregated systems are less expensive.

We know, however, that this type of argument cannot stand close analysis. We know that a dollar figure cannot be placed on the increase in self-esteem that flows from living in an integrated society. Most

importantly, we know that persons with disabilities will no longer accept a segregated society.

Thus, as we plan for the next decade, as we develop programs, we can confidently predict that persons with disabilities will move into the mainstream of American society.

WHO REPRESENTS DISABLED PEOPLE?

Dr. Frank Bowe, Executive Director
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When I think of representation, I see a channeled flow of information: representation of someone to someone. This implies several things, most of them obvious upon brief reflection, most of them, sadly, ignored in actual practice throughout the world. Genuine representation of disabled people, regardless of who does the representing, is remarkably rare. Let me explain what I mean by that.

Before I can represent a group of people, I must first consult with them. This process involves sharing my knowledge or expectation that certain issues among the many that concern these people are likely to become subject to public debate in the near future. I must solicit from these individuals informed opinions on the issues and receive from them instructions to represent their views. These instructions constitute my authority as a representative. To the extent that I act within that authority and on behalf of a body of people, I am helping to further the cause of consumer participation. Those I meet with in my attempts to be a representative can take assurance from the fact that, were they to contact each and every member of the group I represent, they would be told: "Yes, he represents me." And: "Yes, I believe that, and this, and also that."

But I am not done merely with representing the informed opinions of my group to some third party. In order to complete my work as a genuine representative, I must then return to my group and represent to these people the views, decisions, and other deliberations of the people with whom I met on the group's behalf. Once again, I must be certain that I am acting within my authority and that I am accurately reporting upon events. The members of my group can, then, take assurance from the fact that, were they to contact the people with whom I met on their behalf, they would be told: "Yes, he said you believe that, and this, and also that." And: "Yes, we decided upon this strategy for these reasons."

This does not mean that the representative serves merely as a messenger. In its best form, the process involves intelligent representation by an individual who knows his or her constituents well and who is given by them authority to negotiate compromises over a broad spectrum of positions.

Factors Influencing the Representation Process

This process appears quite simple. Indeed, in one sense, it is. Why, then, does it break down so often?

In actual practice, what we see are variations on the following instances:

- The representative presents his or her own views (speaking "off the top of his head");

- No attempt is made to inform the constituents of pending or upcoming issues and to obtain from them their views on these matters;

- No attempt is made to report back to the group on the deliberations of the agency or association;

- Views of a selected few are represented as being those of the constituency as a whole.

Any of these failures will cause eventual collapse of the representation process, together with the credibility of the representative. And these failures are common ones. There are several reasons for this.

First, in many instances, an individual trained to work with disabled people is believed to "know" these people and their needs and desires. Being an expert in a field does not, however, in and by itself grant one authority to represent people. The expert's opinion is an informed one and for that reason is entitled to consideration, but it is still his or her opinion and not necessarily that of others. This distinction is routinely overlooked. Second, informing people of the complexities of issues and obtaining from them their considered views is a time-consuming and arduous process; it is only too tempting to neglect this phase of the work. Third, reporting back to the group can be difficult and even embarrassing if the news is not uniformly good; we all know the fate of the messenger with bad news! Finally, it is unfortunately true that in almost every nation I have visited, more disabled people are "out of the mainstream" than are within the network of disability groups and professional associations. This restriction of the constituency often is exacerbated by the ability of a vocal few to dominate debate and discussion on critical issues. In some cases, favoritism and other tendencies further restrict the body of people actually being represented.

You will notice that to this point I have made no distinctions between representatives who are able-bodied and those who are disabled. All of us are equally susceptible to these problems, and all of us are to some extent guilty of failure to act as genuine representatives.

For all of that, we have found in the United States, and I have seen in other countries, that people who themselves are disabled are generally in a position to be more adequate representatives of disabled people than those who are not disabled themselves. Consumer represen-

tation by consumer representatives by and large has a better chance of doing the job. This may be because the constituency is more inclined to convey authority to "one of us." It may be because agencies and associations consciously or unconsciously confer greater credibility upon persons who are themselves members of the constituency being represented. It may be because a disabled representative brings personal experience to bear upon the issues being considered. Regardless of these or other reasons, I am firmly convinced that we must work together to help disabled people in the nations represented in this congress to select their own representatives.

Scope of Consumer Representation

We must then broaden the scope and depth of opportunities for representation. Within agencies, organizations, and service facilities, clients must be able to represent themselves throughout their rehabilitation process. They must have the right to participate in the design of a program of assistance; the right to appeal any adverse decisions to higher authority; the right to see the results of tests and evaluations; and the right to protection of basic human and civil liberties while a client.

Current and former clients, as well as representatives of the general disabled population (particularly of potential clients) must be able to participate in formulating rehabilitation programs and evaluating their effectiveness. Disabled people must be able to participate in the shaping of government and private agency policies governing the operation of programs and facilities serving disabled individuals. Disabled people who wish to work in fields relating to services for disabled individuals must have an equal opportunity to participate in such work as service providers without undue discrimination on the basis of disability alone. And disabled individuals must be able to participate in government through the same political avenues, including voting, that are made available to others in the society.

As complex as are the questions of <u>who</u> represents disabled people and <u>how</u> that representation is effected, we must not lose sight of the objective to insure <u>that</u> representation takes place. Let that be our charge as we move forward to implement the activities we plan as part of our observance of the International Year of Disabled Persons and as we develop our programs for the Charter for the '80s.

TOWARDS FULL POLITICAL PARTICIPATION

Barbro Carlsson, Consultant on Handicap
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The question of full political participation is in many ways a complicated one, because it relates to the society in which we live. Different countries have different social systems, and I shall be referring to Swedish conditions with which I am familiar.

I am going to consider some of the basic conditions for full participation: knowledge, social experience, and the opportunity to exert influence. Without these prerequisites, a person has little prospect of participation in the life of the community and still less prospect of participating actively in political affairs.

The social and economic conditions of the handicapped vary from one country to another. In some countries, the general material standard of living is such that our living conditions have also improved, even though they still lag behind other people's.

Devaluation of the Handicapped

Generally speaking, although the handicapped have acquired a certain share of the benefits of development, that share has always been limited and there have always been strings attached to it. This is because all communities, rich or poor, single out certain people who are referred to as handicapped.

Why, then, do we eject groups of citizens from the main body of society and allot them conditions inferior to those of other people? How can we accept that some of us have inferior living conditions to others?

It can only mean that different values are placed on different people, some people being valued very highly while others count for extremely little. And it must mean that there are no risks attached to this mode of valuation, because the people who receive low ratings are mostly powerless, with the result that there will be no serious political or other consequences involved if we leave things as they are.

Western societies value their members according to usefulness. The great changes that have occurred in living standards and technological progress have not entailed any profound revision of the way in which we value people.

We still do not take it for granted that all men and women are equal, and this particularly affects those of us who are handicapped.

Even if we live in countries that are wealthy in material terms, we are always likely to be the first to feel the pinch of a worsening economic climate. We are hit faster and harder than other people, because we are at a disadvantage from the very outset.

Handicapping Attitudes

Whatever our material conditions, as handicapped people we are greatly influenced by the human attitudes of the community around us. Our self-esteem and dignity are easily attacked in communities where the strong, the well-trained, and the well-shaped members of society are given praise and prominence and where the traditional view of handicapped people is that they are weak and cannot be expected to contribute to the common cause. Living on these terms, we are easily reduced to cases, objects of care. We are not regarded as an asset, as people who by virtue of their ability have something to offer.

If I am constantly regarded in these terms, it becomes difficult for me to find my human identity, because I am expected, as a handicapped person, to live up to a role shaped for me by others. This reinforces the sense of isolation, the feeling of being apart from others. The human role presents features that unite me with others—our common destiny of birth and death, suffering and happiness. The role of the handicapped person heightens the differences between my life and the lives of other people. This has the serious effect of undermining and weakening my determination to bring about change together with others, a determination without which no genuine change can materialize.

The Importance of Participation

If, therefore, we want a society to exist and function for all its members, they must all be able to participate in this process. They must all be able to influence and participate in decision making. This in turn requires that all of us, whether handicapped or not, acquire the implements whereby we can play an active part as members of the community.

How are we to come by these implements? How can we impart practical and concrete meaning to a concept like solidarity? How can we get to the stage of treating one another with a respect and fairness that show that nobody counts for more than anybody else?

One obvious requirement is that we must fully comprehend each other's positions and specify the aspect of those positions that need changing. We can never accomplish this over the heads of people who have been pushed to one side. Thus, we cannot go on talking about our-

selves, the handicapped, as a class apart, because this would mean setting ourselves up as experts on other people's conditions without admitting that the question concerns the common situation of all of us. We must use our common role as human beings to make good living conditions recognizable and tangible.

People only become handicapped when they are pushed aside. This is when universal rights cease to apply. Thus, where many handicapped persons are concerned, entitlements to housing, employment, education, cultural amenities, and public transport, for example, hold narrower implications than they do for other people. And as I began by saying, we accept this scheme of things.

If we clarify the causes and effects of these conditions, we will have a new point of departure from which to accomplish what is needed in order for a change to materialize, namely, the pursuit of change together with the people concerned and on their terms. This process must be rooted in respect for each person's aptitudes, needs, and potentialities. It must be founded on each individual having the opportunity of expressing his or her own experience and also of developing through access to new experience.

In his book Pedagogy of the Oppressed, Paulo Freire remarks:

> *Every human being, no matter how ignorant and immersed in the culture of silence he may be, is capable of looking critically at this world in a dialogue and encounter with others. Given the tools for this encounter, he will eventually be able to comprehend his personal and social reality and its inherent contradictions, become aware of his own opinion and handle it critically.*

Pedagogy of the Oppressed contains a great deal that is directly applicable to those of us who, being handicapped, are forced into "the culture of silence" by lifelong dwelling in poor surroundings or by severe isolation forced upon us through the inability of our surroundings to communicate with us. This applies, for example, to many adults with severe and composite functional impediments, such as the deaf and blind, the mentally retarded, and the severely disabled. The institution is a total sphere enclosing and enfolding its inmates behind invisible walls that effectively isolate them from one another and from the people outside.

How can people who live in such strictly isolated surroundings or who are otherwise disadvantaged be enabled to exert greater influence and participate in the life of the community? How are we to overcome all the obstacles in present-day society to handicapped persons taking any active part in social affairs, the activities of organizations and associations, and in policy decisions?

Eliminating Barriers to Participation

One of the first answers to this question is that we will have to make decision makers and other members of society more aware of the fact that the resources of all citizens must be utilized if we are to develop our societies and improve our living conditions.

For a long time now we have been making serious efforts in Sweden to give disadvantaged groups, as we call them, greater opportunities for influence and participation in community affairs. This work has been undertaken in the realization that individual measures cannot produce results. Instead, action has to be taken in all walks of life and in various contexts--for example, in early child care, during schooling, and in employment and housing spheres. These reforms have had far-reaching and substantial results. And yet the position of the handicapped in Sweden today is still such that, relatively speaking, we constitute the weak members of society. Above all, this is perhaps because the measures taken, extensive as they have been, have not been sufficient to produce the results intended. The elimination mechanisms in our society are too powerful. We still lack many of the social prerequisites that are necessary to enable us, for instance, to live and dwell independently and on our terms and to be able to work.

What is true of Sweden also applies to other societies. Every society must therefore pay attention to the elimination mechanisms within it. We need this realization in order to avoid constructing societies that handicap their members.

In Sweden, we have regarded adult education and cultural policy as one of our main instruments for achieving greater equality between citizens. Thus, during the past few decades, we have conducted a process of reform in this sector aimed at bringing adult education and culture to new and disadvantaged groups, i.e., the undereducated and handicapped.

We have seen that adult education can, above all, provide a useful aid to handicapped people in their struggle for recognition and greater influence. We believe that serious efforts along these lines are capable of helping to influence the living situations of the handicapped in a more total perspective, provided we actually reach the groups that are most impeded from taking an active part in education and social affairs.

To succeed in this, we must actively approach the people we want to reach. Outreach or activation schemes of this kind are being conducted in Sweden on an experimental basis. The most important lesson we have learned from these experiments is that the activators must come from the organizations representing the people to be activated--associ-

ations of the handicapped, immigrant associations, trade unions, and so on. The activators must have experiences in common with the people they approach, and they also need to know about all the various social phenomena that interact with adult education.

The needs of handicapped and other undereducated persons demand completely new educational and cultural forms with different content of a different quality. It is in response to these new needs and demands that adult education and cultural activities will be able to grow and develop in the future. Above all, we have an opportunity here to test the positive implications of the task of promoting positive developments for the least privileged members of society.

In order for us to participate politically, freedom of expression must apply to all of us. This means, among other things, that we must have access to books, newspapers, and periodicals and to the things that are said on radio and television. This may appear so self-evident as to require no pleading, but there are so many of us with vision and hearing defects and other impediments to information who have very limited access to the spoken and printed word. Our ability to obtain information and express ourselves freely is, of course, bound up with other factors besides access to the spoken and printed word. To us, the handicapped, this question is particularly bound up with the extent of our isolation. In these connections, however, access to the spoken and printed word can be one of the tools whereby we free ourselves from a condition of oppression and dependence on others.

The Role of Handicap Organizations

The course paved by developments in Sweden will, to a great extent, depend on the ability of the associations of the handicapped to assert the interest of their members. Year by year these associations have gained strength as lobbying and opinion-forming organizations for the establishment of greater fairness and equal conditions between the members of Swedish society. Their combined membership now totals some 250,000 as compared with a national population of eight million.

The work of the associations of the handicapped has been of great importance to the groups represented, but it has also helped to give clearer meaning to such concepts as solidarity, participation, and equality. The International Year of Disabled Persons in 1981 will have as its motto "full participation and equality." This demands that we continue with undiminished vigor our effort to improve the possibilities for underprivileged citizens to obtain different and better conditions on a basis of participation with others.

Conclusion

It is only with the participation of the handicapped themselves that our reality can be described and thus eventually changed. In order for community work to be able to continue and develop, a greater number of handicapped persons must take part in it. Therefore, it is vitally and urgently necessary that vigorous efforts be made both nationally and internationally to facilitate the active participation of handicapped persons in organized cooperation, so that on this basis we will be able to achieve full political participation.

This is all the more important at a time when we can expect increasing competition for common resources. In a situation of this kind, special attention needs to be paid to the situation of vulnerable groups and to strengthening their position in society.

Our efforts to promote participation and equality must also be based on the common characteristics of our role as human beings. Together we must define common and fundamental needs such as housing, employment, and education--needs that are the same for all people. Together we must work to provide everybody with the necessary ingredients of human dignity and a life worth living.

This is possible if we are prepared to recognize other people's living conditions as our own and join forces in changing them. Development in this direction is possible, and it will benefit people and societies all over the world.

DISABILITY RIGHTS ISSUES: THE ROLE OF ADVOCACY IN GOVERNMENT

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The proliferation of government programs for handicapped people, coupled with a rapidly emerging organized disabled rights movement, has led to the need for coordination, information, referral services, and, most importantly, advocacy programs at all governmental levels. As the disabled community has become more politically active and sophisticated, pressure has increased on government to establish a comprehensive policy on programs and issues affecting this sector. This pressure frequently manifests itself in the creation of advocacy agencies or programs that focus on a wide spectrum of issues and concerns of disabled people that government is, or should be, concerned with.

Definitions

To better understand the role of advocacy in government, we must first examine the current definitions, concepts, types, and methods of advocacy. Webster defines the word "advocate" as "one that pleads the cause of another." The Joint Accreditation Council of Services for the Mentally Retarded and Other Developmentally Disabled Persons defines advocacy as "the representation of the rights and interest of oneself or others."

Advocacy implies a philosophy of positive convictions and actions leading toward resolution of issues and problems, improvements in individual or group circumstances, and/or changes in existing systems so as to make them more responsive and responsible to their constituents or to those they were designed to serve.

There are three basic types of advocacy:

Self-advocacy: An individual advocating for a cause on his/her own behalf.

Individual Advocacy: An individual advocating for and on behalf of another person.

Group Advocacy: A collective of persons generally clustered within an interest framework to act conjointly for a cause or causes.

There are two types of advocates:

Lay Advocates: Persons outside of government who possess

little, if any, formal training in advocacy techniques and skills, who practice in the voluntary sector of society, and who may or may not receive compensation for their efforts and actions.

Professional Advocates: Those who are skilled in the techniques of advocacy through formal training and/or experience and who receive compensation for their efforts and actions.

There are three types of advocacy processes:

Case Advocacy: A method based on the use of skills and techniques, usually in a one to one type of situation and that, when necessary, resorts to use of court systems.

Systems Advocacy: A method using various skills and techniques to bring about desired improvements and/or change in society or government or their components.

Governmental Advocacy: A method practiced within a government setting that uses a variety of skills and techniques within a planned programmatic framework that is designed to accomplish specific goals and objectives related to the population it is advocating for. Governmental advocacy may be internal or external. Internal advocacy is directed toward goals that enable a department or agency to act more responsively and relevantly in meeting the needs of and providing services to a specific population. External advocacy is directed toward other programs in the government or the private sector. Within this context, the term "ombudsman" is defined as a government official who investigates and remediates citizen complaints.

The world around us is replete with examples of advocacy. Organized advocacy can be found in the United Nations, the press and other media, legislatures, executive branches, and pulpits, to mention but a few. It can employ methodologies as diverse as political action, research, public education, passive resistance, and in its extreme, violence and terrorism. In fact, we are influenced every day of our lives by advocacy and the actions of advocates.

The Growth of Advocacy in the Handicapped Community

All this knowledge and information about advocacy does not explain why, when we use the term "advocacy" today, we are speaking of the handicapped community. Historically, advocates have been the parents

and families and other sympathizers of disabled persons who sought for and fought to help achieve the potential they perceived in disabled persons. They are still advocates, but now they are joined by the members of the disabled community who have learned to advocate for themselves and for their, as yet, less sophisticated brothers and sisters.

The constant frustrations of handicapped persons to be accepted as equals, their search and struggle to obtain vital services to realize their aspirations, and their need to join with others who have the same basic needs and desires has, with the years, given life and meaning to the word: advocacy. It is the word of the handicapped community; it is identified with them.

Until the early 1970s in the United States, there were many groups of disabled people, each group concerned with its own disability and oriented towards its own goals. The accomplishments of the minority civil rights movement of the 1960s influenced the individual disability-oriented organizations, stimulating a greater self-identity and enhanced awareness of the political effect that could be achieved in unity. While maintaining their own individuality, these groups, working together towards common goals, are realizing that their strength and energies are enhanced and that collective power can bring about positive change for them in society and government. When we identify advocacy with handicapped people, we acknowledge the battles waged for services and recognition, the hard knocks received in the process of growth and learning. We acknowledge the experience and expertise gained by the handicapped community to obtain its fair share in every phase of life that is rightfully theirs.

The Growth of Advocacy in Government

Government is designed to insure the rights of, and provide services to, varying publics through implementation, administration, and enforcement of laws, regulations, and programs. Inherent in its responsibilities is the function of advocacy. Often, however, governments narrowly define their roles, seemingly excluding the function of advocacy, particularly for a specific population if it is not politically visible and active.

Government exists by laws to protect the rights of its people and to provide an order and system of living for its people. How then can and should government provide this order and system for a population (the disabled) that until recently has not been considered a political constituency. Because this particular constituency was not being adequately served by most facets of governments, steps needed to be taken to make government aware of its responsibility to disabled citizens. These steps were initiated in different ways and resulted in various

types and structures of advocacy programs in all levels of government, but always because of the pressure applied by a concerned citizenry.

In the federal government of the United States, various forms of advocacy programs "for handicapped people" developed over the past years. Rehabilitation programs, special education programs, the President's Committee on Employment of the Handicapped, the President's Committee on Mental Retardation, and various advisory committees and task forces are but a few of these programs. In the main, these efforts excluded input from and the involvement of those on whose behalf advocacy was being done. The Rehabilitation Act of 1973 (P.L. 93-112) as amended by the Rehabilitation Act Amendments of 1974; the Mental Retardation Facilities and Community Mental Health Centers Construction Act, as amended by the Developmental Disabilities Services and Construction Act (P.L. 91-517 and P.L. 94-103); and the Education for All Handicapped Children Act of 1974 (P.L. 94-142) all gave impetus to a changing role for the federal government in the area of advocacy by providing some funds for individual and group advocacy programs within the states and by requiring the involvement of disabled consumers in the policy development and consultation aspects relative to program services.

Several specific events of the past few years have further supported the need for a designated advocacy program within the federal government of the United States. These events have included political efforts of some disabled people in the presidential campaign of 1976, the advocacy activities of disabled people leading to the signing in April 1977 of the Section 504 Regulations for the Rehabilitation Act of 1973, and the White House Conference on Handicapped Individuals in May of 1977 with its recommendations calling for a firm commitment on the part of federal government to adopt programs of advocacy with disabled people.

A plan to create an advocacy program with, and for, disabled people within the federal government was proposed by the Commissioner of the Rehabilitation Services Administration (RSA) with the accompanying endorsement and support of the presidential administration. The unit assigned this responsibility is the Division of Advocacy and Constituent Relations in RSA's Office of Advocacy and Coordination.

The mission of the National Program of Advocacy is to promote, protect, and guarantee the rights of disabled individuals; to insure the participatory involvement of disabled people in all aspects of decision-making processes as these relate to policies and programs in the federal government; and to insure that all programs and services are relevant to promoting the equality, opportunity and independence of handicapped persons, to fostering the development of their potential and growth, and to insuring their participation in and acceptance into the mainstream of society.

Groups Addressed through Advocacy

In order to accomplish this mission, the National Program of Advocacy (based in the Rehabilitation Services Administration) must, through various programs, address five major publics and bring them together to work toward common goals as stated in its mission. These publics include:

1. *The disabled community*, consisting of current clients receiving services through federal or federally funded programs, or state funded and sponsored programs; disabled individuals who at one time received services from such programs; all other disabled individuals who potentially might use or be affected by such programs; and any other individual with a disability defined in the Rehabilitation Act of 1973, as amended.

2. *Rehabilitation professionals*, consisting of all personnel within RSA, state rehabilitation agencies and programs, and developmental disability programs and councils at state and local levels.

3. *The voluntary sector*, consisting of all private service providers of national, state, or local scope and professional organizations and associations providing services to, or interested in, fostering the concerns of people with disabilities.

4. *Government personnel*, consisting of all persons administering programs within federal, state, or local governments that directly, indirectly, or potentially affect disabled people.

5. *The general public*, consisting of interested and potentially interested persons whether or not they are directly concerned with disabled persons.

To be effective, a national program of advocacy must address and continually work with these publics in a cross-cutting fashion. To implement its cross-cutting efforts, a certain degree of flexibility is needed within the program and within the duties and responsibilities of professional staff. This flexibility demands that the leadership of the advocacy program develop and maintain continuous coordination of staff resources.

How then does advocacy in government function and how specifically for disabled people?

Political Aspects of Advocacy within Government

First and foremost, advocacy within a governmental structure functions in a political manner, at the sufferance of the political

leadership in question, along rules either clearly structured or at least implied. It is critical to understand the full implications of the elemental difference between advocates outside government, and organized, identified, officially sanctioned advocates within government.

A political system exists in part to perpetuate its own existence and survival. Government as both a creature and agent of that system, responsible to both laws and political leadership, exists in a fragile balancing act. In essence, government has to "render unto Caesar" in sometimes conflicting ways. Add to this an ingredient of independence, autonomy, and critical leadership on behalf of a specific cause or population and one begins to see the potential for conflict which every earnest advocate in government must acknowledge and be ready to accept.

In short, the advocate within government operates under severe and constrained limitations. In most instances, advocates for disabled citizens are appointed by either an elected executive or a high official within the executive branch of government. Hence, they are responsible to the elected official as well as to the disabled constituency.

This "walking the razor's edge" can and often does result in a political and moral conundrum for the individual who, while "serving two masters," still has a professional obligation to solve the problem at hand in a fair and equitable fashion.

The key word in this discourse is "professional." Not professional as would be thought of in the traditional sense, for the advocate in government is continuously redefining his or her role and operational methods. Rather, a professionalism born out of the necessity to implement real and meaningful change using the tools, systems, programs, and laws emanating from the political and governmental relationship.

It is this basic commitment to the system, including its manipulation to make it work effectively and, where necessary, to alter it in order to keep it current, that must be the hinge from which all advocates operate.

To illustrate the above, one can examine a situation whereby the threatened members of one segment of the disabled community are organized around an emergency issue vital to them. With the assistance of the government advocate, this group researches and drafts a solution to the emergency issue which is then presented to the appropriate officials. Through this process of solution development, the ad hoc community can and often does achieve cohesion and legitimacy it might not achieve independently. The proposed solution also gives the advocate credibility as technician and leader and helps to instill a faith in his or her constituency that government does work or at least does try to work.

An illustration of the above can be demonstrated in a situation that occurred in New York City in 1974 over the issue of odd/even gasoline exemptions. The local advocacy governmental office for the handicapped prepared a comprehensive gasoline rationing plan enumerating who should receive exemptions, how the process should work, and why it was critical to do this. An ad hoc community group was formed with the help of the government office, and an organized plan of action was developed to reach the appropriate state officials with the agreed upon solution as a basic framework for negotiation. The end result of this operation was the inclusion of disabled drivers and other vehicle-dependent disabled individuals into the already implemented state gasoline rationing plan. In short, the system was manipulated, altered, but used to solve a grave emergency affecting hundreds of thousands of individuals.

How the officials were reached and convinced to act is, however, an illustration of another basic principle for government advocates. It involves use of the political system and media, which are, in my opinion, a legitimate and necessary part of every advocate's skills and techniques, provided they are used with honesty, accuracy, and diplomacy.

The basic strategy agreed upon by both advocates and community was a massive demonstration in front of the governor's local office, with contingency actions calling for disruption of traffic and passive resistance if necessary. Again, it must be remembered that the situation was grave and was an emergency recognized even by local elected officials who were legally powerless to change it. The situation was further heightened by the fact that it was an election year in the state and the incumbent governor was running for reelection.

Clearly, the official local government advocates could not participate in anything illegal. Just as clearly, these same advocates had a responsibility to advise their community on the dangers of provocative actions. But clearest of all was their responsibility to support and protect their community once a consensus for action had been reached and to use this situation to achieve the objectives agreed upon.

The actual result of the demonstration was twofold. Using passive resistance, the ad hoc group of disabled people tied up traffic on a busy major street. This event was covered fully by all media, bringing public attention to their cause. This action culminated in a meeting between the state's highest energy official and the representatives of the ad hoc group of disabled constituents along with the advocates on the following morning, resulting in the previously mentioned solution. There may be some, indeed perhaps many, who may be shocked and offended at the preceding illustration as a legitimate example of how advocates within government should comport themselves. But lest you be too harsh on those of us who have had to face the realities of political unconcern, try to remember these simple precepts:

- The political system is both part of and separate from government. Because government is dependent on the political system and influenced by it, it must provide a legitimate area of operating when the more traditional means fail.

- The advocate in government cannot condone or actively support illegal actions no matter how justified they appear. But the advocate has to actively support the constituency when it independently agrees on a set course of action by constantly being the mediator, buffer, and communications link between the parties.

- The advocate must keep the agreed upon objective clearly in mind.

The above example is also, it should be remembered, a rather dramatic one. In one sense, it reflects very clearly the political and moral conundrum mentioned earlier. In another sense, it is certainly not typical of the daily kinds of activities that governmental advocates for disabled individuals are engaged in.

The Variety of Government Advocacy Programs

The local entities, in general, have become responsible for a broad range of issues and programs that heretofore have not been historically associated with the most critical needs of disabled people. It is in large part a tribute to the rehabilitation effort in the United States that many disabled people in becoming employable, educated, and independent, are now more vitally concerned with problems involving civil rights, housing, transportation, jobs, energy, crime prevention, voting rights, and freedom of life style than with more traditional medical and health concerns.

Advocates in government have had to become proficient in a wide range of programs and problem areas. In effect, the staffs of these agencies have had to become generalists in a field heretofore dominated by specialists. By the same token, they have also had to become specialists in areas where none existed before. If there is a basic philosophical underpinning to this kind of approach, outside of sheer necessity, it is that disabled Americans have the same broad and complex array of needs as all other citizens. In addition, integration of disabled people into the full, rich fabric of our national life means that all aspects of life have to adjust and adapt in varying degrees to accept them and allow them to thrive.

At this point in time, there are approximately 250 local advocacy programs for handicapped and disabled individuals in the United States. Similar offices exist at the state level in many states, as do governor's committees for the employment of the handicapped. In addition to

these agencies, federal law has mandated the establishment of protection and advocacy agencies for developmentally disabled persons in each state. An advocacy program has been developed in the Rehabilitation Services Administration to deal with a wide range of issues affecting disabled citizens. In other federal areas, the long established work of the President's Committee on Employment of the Handicapped and the more recently established Architecture, Transportation, and Communications Barriers Compliance Board and the Office of Independent Living in the Department of Housing and Urban Development have significant advocacy functions as part of their responsibilities.

It is significant to note that these examples of government advocacy programs vary widely in the type of advocacy they provide, whom they serve, the issue areas they focus on, the powers they have at their disposal, and the structure in which they are housed. Space does not allow for an in-depth description and comparison of these various federal activities. Specific descriptions of these programs can be obtained by requesting them from the Office of Special Education and Rehabilitation Services, U.S. Department of Education, Washington, D.C. 20001.

The Rehabilitation Act Amendments of 1978 further mandate the extension and expansion of advocacy activities and programs for disabled individuals. This Act, among other things, provides for the expansion of the client assistance programs from the status of demonstration programs to actual programmatic activity. Title VII of the Act provides for the establishment of independent living programs, as well as protection and advocacy programs for adult disabled individuals in the broad rehabilitation system. Title VII advances the concepts and philosophy inherent in disability advocacy and permeates many of the service programs within the public and private programs.

Government, it must be remembered, is comprised of people who bring their conscious and unconscious attitudes, biases, and feelings with them into the execution of their duties. Therefore, it can be fairly stated that government itself can have and does exhibit attitudes towards issues, problems, and people.

Because disabled citizens are now approaching government in fundamentally different ways for fundamentally different services, the advocate has to be acutely aware of what the attitudes of officials and policymakers are in regard to the disabled community. It is in this regard that consultation within government on the part of the advocate becomes critical. This consultative process is the most basic and constructive way for the advocate to address misconceptions and prejudice stemming from personal beliefs which influence policy.

The "Politics of Impotence"

The disabled community today is still an extremely fragmented community beset by major problems. Like other minority groups before it, it has begun a slow, but deliberate, movement towards involvement in the American political process. To date, most of this effort has been nonpartisan in nature, and it has been divisive and educational. Part of the divisiveness is understandable and predictable. It is part of a syndrome I call the "politics of impotence," and history abides with too many examples to list here.

The basic causal factors underlying this concept of the "politics of impotence" deserve to be identified. They are essentially manifestations of the natural instincts of a group of individuals who, in different ways and for different reasons, have been systematically cut off from the mainstream of society. As they have gained a measure of control over their own lives, they have had to confront a society and world that seems both alien and hostile to them and their needs. Simultaneously, they have been dramatically affected through the media and in other ways by the other contemporary civil rights movements. The aims are all basically the same - justice, dignity, self-determination, equal opportunity. The difference has been in the level of options and opportunities available from childhood on to disabled Americans. The difference has also been the difficulty in utilizing psychological self-help devices stressing commonalities such as age, skin color, background, and sex as a source of unity and pride. Combine these with systematic segregation, and the end result has been a preoccupation with theory and rhetoric at the expense of organization and action in the larger society.

Conclusion

Despite this, the signs are clearly evident that at long last disabled Americans are realizing that they must take the initiative and interject themselves into the mainstream of American political life in order to attract the kind of responsiveness and action they want from government.

I maintain that this evolution into politics is imperative, inevitable, and now underway. As it develops, so will the authority and impact of the advocates in government. Most importantly, the social fabric of the United States will change and embrace one more group of her forgotten people--Americans with disabilities.

V.
People with Disabilities: Coming Together Internationally

We have looked at a variety of models and issues in consumer participation from several national perspectives. Now we will discuss consumer participation internationally. Several questions arise immediately. Can the leaders in the disability movement look beyond their own national models, philosophies, and priorities to work together on international disability concerns? What issues can be identified as being of major concern to disabled people worldwide? What type of organization and philosophy can disabled people from all over the world agree upon?

DISABLED PEOPLE: COMING TOGETHER INTERNATIONALLY

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"Vegetables of the world unite" doesn't sound like the rallying cry of an international organization of disabled people--but it was. It became a symbol to the disabled people who attended the 1980 World Congress of Rehabilitation International in Winnipeg--a symbol of the attitudes that disabled people everywhere are still battling. Something happened at that meeting that has never happened before; an organization was formed as a result of the activism of the disabled people at Winnipeg that aspires to be the largest cross-disability organization in the world.

What happened? On the first evening of the World Congress, Monday evening, COPOH sponsored an international exchange that was attended by over 300 people with disabilities. The purpose of this meeting was to share information about the activities of people with disabilities in the various countries. People with disabilities from Sweden, Canada, Denmark, Zimbabwe, Finland, the Netherlands, Hong Kong, Japan, Israel, India, and South Africa spoke about the situation in their countries.

The three-hour meeting developed into an awareness session. After listening to descriptions of national structures for the involvement of disabled people, legislation for disabled people, and the independent living movement, everyone listened to a disabled person from a developing country describe the situation of his friends having no wheelchairs and having to crawl as a means of mobility. Every disabled person in that room became aware of the diversity of situations and ideologies that face disabled people in the world.

The result of this new awareness and the shock of the situation (for people from developing and developed countries) was energy, enthusiasm, action! Henry Enns and Allan Simpson from the Canadian Coalition of Provincial Organizations of the Handicapped have summarized the events leading up to the formation of a world coalition of persons with disabilities, Disabled Peoples' International, in "Decade of Destiny of and for Handicapped People:"

> The air was pregnant with expectation. A tremendous roar filled the Convention Center in Winnipeg, Canada that Monday evening, June 23, 1980. The question was repeated: "Do I hear you say you want a world coalition of citizens with disabilities?" The unanimous response came back, echoing to every corner of the World Congress of Rehabilitation International--"Yes." The some three hundred handicapped delegates who were gathered there from all parts of

> the globe had a sense of their own destiny. They wanted to proclaim their rights, as citizens, to an equal voice in the decision making of services, the policies and programs that affected them.

A delegate from the United States articulated what was on every participant's mind:

> I hope this meeting and this week will mean that we can start now making the linkages and planning the coalition of the world of disabled people and international exchange visits of disabled people. That we can start now planning for information and programs to build an integrated world and a society in which all people are equal in sharing the resources of this world. And there are no developed and underdeveloped, and no privileged and nonprivileged societies as we have now.

A steering committee was organized to prepare a basic structure for an organization. COPOH distributed a daily newsletter to communicate the disabled person's point of view about the congress. Updates were given about the coalition's steering committee and general organizational planning sessions, as well as recognizing nondisabled participants of the congress who indicated support (or nonsupport) of the philosophy of the coalition. On Wednesday, June 25, a second meeting of disabled people was organized to discuss the proposals developed by the steering committee. Henry Enns from Canada was chosen as the chairman and Bengt Lindqvist was chosen as vice-chairman. Sweden offered to fund most of the organizational expenses. The steering committee consisted of Mr. Enns, Mr. Lindqvist, Jim Derksen from Canada, João Ferreira from Costa Rica, R. Jabbar from India, T. Komori from Japan, and Joshua Malinga from Zimbabwe. The following is an excerpt from that evening's report as unanimously passed by the attendees.

1. Name of Organization: World Coalition of Persons with Disabilities*

   The words "disabled" and "handicapped" will be used interchangeably. However, each word has a different emphasis. "Disabled" refers to the physical or mental limitation, while "handicapped" refers to the interpretation and limitations put on by society as a result of the disability. "Handicap" also incorporates the component of equalization as in a horse race.

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*The name has been changed to Disabled Peoples' International.

2. Membership and Definitions

The membership is open to all organizations "OF" handicapped people. This means that the decisive control of the organization should be in the hands of the handicapped. Decisive control means a majority of the governing board or council as well as the general membership be handicapped.

The definition of handicapped in this case would include physical and mental disabilities. In the case of the developmentally disabled, it could also include the parents or other advocates. Further criteria for membership will be developed by the steering committee and established at the first annual meeting of the organization.

3. Philosophy and Purpose

The World Coalition of Persons with Disabilities should be based on the philosophy of equal opportunity and full participation of handicapped people in all aspects of society as a matter of justice rather than charity. It should be based on the principle of integration. This means that all services in the community, such as transportation, housing, employment, education and recreation, be made accessible for handicapped people as a matter of right. It is important that recognition and legitimation of this principle be accepted by all people. Hand in hand with this principle is the emphasis that handicapped people have an equal responsibility with the rest of society. This means that the expectations to find employment, seek training and organize their own independent situations be accepted as "normal."

This means the expectations of the sick role are to be abandoned and handicapped people are expected to fulfill all the obligations of the adult role in varying societies. Furthermore, the philosophy of the organizations should be to strive towards unity among handicapped people and their organizations worldwide and to encourage mutual cooperation, assistance and understanding among all people. The organization should be particulary concerned with developing handicapped organizations in the developing countries and in developing self-help efforts in these countries. The coalition should be firmly committed to the principle that handi-

capped people are their own best spokespersons. Therefore, the organization should be made up of organizations "OF" the handicapped rather than "FOR" the handicapped. The control of handicapped people is not meant to be exclusive. It should be the philosophy of the organization to work with all persons and organizations to improve the living conditions of handicapped people around the world - particularly in the so-called "third world" countries.

4. Goals and Objectives

a. To provide a forum for exchange of information and personnel internationally, particularly qualified handicapped advisors in program development such as employment, transportation, education, housing and technical aids, etc.

b. To be a voice for persons with disabilities at the international level, particularly keeping in mind the developing countries.

c. To monitor and evaluate existing legislation, programs and services affecting handicapped people and to work for changes in a constructive manner, clearly pinpointing weaknesses and gaps and providing alternatives.

d. To stimulate the creation of organizations "OF" handicapped people all over the world, particularly in the developing countries.

e. To promote solidarity on a worldwide scale, particularly keeping in mind the developing countries.

f. To be partners in planning and decision-making in all services affecting the lives of handicapped persons.

g. To provide a vehicle for public education concerning handicapped people at an international level.

h. To provide a vehicle for "self-help" for handicapped people.

5. Mandate of Steering Committee

To ensure that continuing steps be taken to develop a

world organization "OF" handicapped people. This would include the following:

a. To draft a constitution

b. To plan and organize a world conference in 1981, IYDP. The conference would have a two-fold purpose:

   1) To create a gathering of handicapped people during the International Year of Disabled Persons 1981, similar to the Women's Year in Mexico.

   2) To start the world coalition.

The steering committee should concern itself with the situation of the handicapped in the developing countries in program planning and seeking funding.

c. To make contact with other organizations of handicapped persons on both national and international levels.

d. To explore all possible sources of funding and other resources to start the organization. It is important to have representatives from all countries. It is important to make this possible financially.

e. To research and explore relationships to other international organizations.

f. To be the vehicle of negotiation with Rehabilitation International and the United Nations concerning the Charter of the 80's and the IYDP.

6. Relationship to Rehabilitation International

We compliment Rehabilitation International for making possible the vehicle for the formulation of the world coalition. We look forward to a working relationship with them, keeping in mind that as a consumer organization we have a particular perspective to add to the planning of rehabilitation services. Also, it is important to our organization to keep in mind that we are concerned with a much broader range of services than rehabilitation - services such as transportation, employment, accessiblity, education and housing do not

> fall under the umbrella of rehabilitation services. A mandate has been given to the steering committee to explore future relationships with other international organizations and bring a report to the first world conference of the coalition.

Before the congress adjourned, an international organization of disabled people had begun. The steering committee had expanded and now included representatives from Argentina, Canada, Costa Rica, Sweden, Ireland, Zimbabwe, Bahrain, Japan, Australia, United States, Singapore, and Mauritania. In October of 1980 the steering committee met in Dublin, Ireland, the constitution was developed, the name was changed, and a conference was proposed to be held in Singapore late in 1981. The meeting in Singapore will be the first meeting of the Disabled Peoples' International. The steering committee met again in February 1981 in Berkeley, California, U.S.A. and continued planning the conference.

Just another organization? Are the rights and participation of disabled people too dependent upon the specific situations in each country for there to be any common models? Is this just another one of those organizations for people to organize, promote, tire themselves out, and then leave? What does a person from a Canadian disabled group that is fighting for integration of transportation services have in common with a person from Zimbabwe who watches his fellow disabled people crawl because they have no wheelchairs? What can such an organization do?

Most of the disabled people who attended and participated in the organization of Disabled Peoples' International have asked themselves these questions. Although they may not have the answers yet, they do have an interest, and a commitment. No matter what part of the world you live in, how active you are, or how integrated into society disabled people may be, a disabled person never stops trying to improve situations for other disabled people.

Many local-level disabled consumer groups spend months working on the very basic structures, philosophies, and issues that face their organization. The fact that these basics were resolved in two days in Winnipeg by five people representing diverse cultures demonstrates the sort of commitment that each person who attended the meetings of disabled people in Winnipeg has for bettering the lives of people who are like them. One could not attend the meetings, read the newsletters, and listen to the hopes without feeling much closer to disabled people in other countries--and changed.

Appendices

A: Analytical Index
B: List of Presentors

Appendix A
Analytical Index

•SELF-DETERMINATION OF HANDICAPPED PEOPLE, Dr. med. Marianne Fritsch, Federal Republic of Germany

•SOME REFLECTIONS OF A DISABLED PERSON ON THE SITUATION IN FRANCE, Bernard Lesigne, France

•THE RIGHT TO ALL TYPES OF INFORMATION, Karl-Erik Karlsson, Sweden

•THE RIGHT TO WORK: A POLITICAL ISSUE, Bengt Lindqvist, Sweden

•CONSUMER GROUPS: THEIR ORGANIZATION AND FUNCTION, Allan J. Simpson, Canada

•CONSUMER GROUPS: THEIR ORGANIZATION AND FUNCTION, Ron Chandran-Dudley, Singapore

•ORGANIZING AN ACTION GROUP, John Simkins, England

•TRADE UNION PARTICIPATION, Liam Maguire, Ireland

•HANDICAP COUNCILS: A SWEDISH EXPERIMENT, Linnéa Gardeström, Sweden

•PARTICIPATION OF HANDICAPPED PEOPLE IN THE PLANNING, IMPLEMENTATION AND MANAGEMENT OF REHABILITATION SERVICES, Pieter J. Blommestijn, Netherlands

•POLICY ISSUES IN INDEPENDENT LIVING REHABILITATION, Donald E. Galvin, Ph.D., United States

•CROSSROADS CARE ATTENDANT SCHEME TRUST, Dr. Richard Hudson-Evans, England

•NATIONWIDE TRANSPORTATION SERVICE: A SWEDISH EXPERIMENT, Per-Olov Kallman, Sweden

•HIGHER EDUCATION OPPORTUNITIES, Kalle Könkkölä, Finland

•DIAL UK: DEVELOPMENT OF THE NATIONAL ASSOCIATION OF DISABLEMENT INFORMATION AND ADVICE SERVICES, Ken Davis and James I. Woodward, England

•THE INFLUENCE OF THE HANDICAPPED BY MEANS OF THEIR OWN ORGANIZATIONS, Bruno Landstedt, Sweden

•THE DISABLED CONSUMER MOVEMENT: POLICY IMPLICATIONS FOR REHABILITATION SERVICE PROVISION, Jim Derksen, Canada

•FROM CHARITY TO INTEGRATION: A NEW FUTURE FOR PERSONS WITH DISABILITIES, Edward V. Roberts, United States

•WHO REPRESENTS DISABLED PEOPLE?, Frank G. Bowe, Ph.D., United States

•TOWARDS FULL POLITICAL PARTICIPATION, Barbro Carlsson, Sweden

•DISABILITY RIGHTS ISSUES: THE ROLE OF ADVOCACY IN GOVERNMENT, Eunice K. Fiorito, United States

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Historical Perspectives
Independent Living
Organizational Models
Policy Issues for Disability Organizations
Reference to Laws
Service Integration or Segregation
consumer group
consumer
partici-pation
disability
handicap
consumer ethic
advocacy

Appendix B

List of Presentors *

Mr. Pieter J. Blommestijn
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Dr. Donald E. Galvin, Director
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Mrs. Linnéa Gardeström, Director
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(Dr. Hudson-Evans is the founder and trustee, Crossroads Care Attendant Scheme.)

Mr. Per-Olov Kallman
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Mr. Karl-Erik Karlsson
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(Mr. Karlsson is also president of the National Association of the Deaf in Sweden.)

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*Titles and addresses of presentors were current as of June 1980.

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UCIR

University Center for International Rehabilitation

University Center for International Rehabilitation (UCIR) is located at Michigan State University and is funded by the National Institute of Handicapped Research, U.S. Department of Education, Washington, D.C.

The Research, Information and Education/ Training Divisions of UCIR work together to make international information available and useful to domestic rehabilitation. Information which is assessed as highly relevant, is disseminated through media, formal training of graduate students, and nonformal training such as workshops and seminars.

UCIR is especially interested in exchanging information with other countries regarding:

. Programs and services that help disabled people to live more independently
. Implementation of the new functional assessment scale of disability measurement developed by the World Health Organization
. The participation of handicapped people in the rehabilitation process
. Behavioral characteristics and environments associated with individuals who successfully cope with disability
. Barriers to the importation of technological devices
. Educational resources for the development of rehabilitation and special education curricula

Other aspects of the UCIR program include the award of graduate assistantships to U.S. and foreign students pursuing degrees in rehabilitation and related studies at Michigan State University, a course series with internships in international aspects of rehabilitation and technical assistance to foreign universities in program development and faculty training.

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Rehabilitation International®

Rehabilitation International is a federation of 115 organizations and agencies carrying out programs for disability prevention and rehabilitation. The members are located in 64 countries, and 8 international associations are also affiliated.

The world body, founded in 1922, has its headquarters in New York and operates detached secretariats for various specialized functions in Bombay, Cologne, Copenhagen, Pittsburgh, Stockholm and Vienna. The Rehabilitation International Informational Service distributes from Heidelberg, and there is a Spanish-language satellite in Mexico City. The *International Rehabilitation Review* is published quarterly in New York and the *International Journal of Rehabilitation Research* is published in the Federal Republic of Germany.

Rehabilitation International maintains official relations with the United Nations Economic and Social Council, the World Health Organization, the International Labour Office, UNESCO, UNICEF, the Organization of American States and the Council of Europe. It provides the secretariat for the Council of World Organizations Interested in the Handicapped, a coordinating body of 40 international organizations working in the field of disability prevention and rehabilitation.

The principal activities of Rehabilitation International and its subsidiary bodies are to assist in and support the development of organizations and programs for disability prevention and rehabilitation, to assure an effective international exchange of information for this purpose, to encourage the improvement of national legislation in its field, to organize international technical meetings and world congresses, and to give or stimulate technical assistance for projects related to its purposes.

Norman Acton, Secretary General
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